

A Community Based Participatory Research Approach to Create a Diabetes Prevention  
Documentary for Māori

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*Co-operation can accomplish many things which no individual could do alone*

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## **Abstract**

### **A Community Based Participatory Research Approach to Create a Diabetes Prevention Documentary for Māori**

#### **Abstract**

Type 2 diabetes is almost three times more prevalent in the indigenous people of New Zealand (Māori) than non-Māori. Despite the high rate of diabetes there is a low level of diabetes knowledge and awareness in the Māori community. Several studies of Māori health identify a need for new health communication approaches to diabetes prevention in order to reduce the gap between Māori and non-Māori disease rates.

Several problems can be identified with existing health promotion and education materials about type 2 diabetes for Māori. There is a gap in the literature reporting on what constitutes a culturally appropriate research process for health communication with Māori. A second problem is a difficulty ascertaining how and if health behaviour theory was selected when designing health promotion materials for type 2 diabetes with Māori. There is a need to make explicit the research process and employment of theory in the design of health promotion materials. In addition, little is known about how Māori understand or experience type 2 diabetes, or the social and cultural meaning given to the disease. These are significant gaps because a tenet of effective health communication is the need to engage with and understand how cultural, social, environmental and historical factors influence health behaviours.

The research objective was to ascertain how Community Based Participatory Research (CBPR) in combination with indigenous principles and behavioural theory could be employed to create a culturally appropriate resource for Christchurch adult Māori at risk for type 2 diabetes. This study describes the rationale for and process of working in partnership with an indigenous population to develop a health communication resource that reflects Māori beliefs and cultural practices.

Principles of CBPR were applied to a qualitative research design employing community engagement and partnership, key informant interviews and hui (focus groups) to inform the messaging of a diabetes prevention documentary. In order to decolonise the research process, Walters et al.'s (2009) "indigenist" research principles were incorporated into the research design and evaluation.



The research findings revealed diabetes prevention is a complex and multifaceted problem in the Māori community. There was a clear lack of knowledge and understanding about the causes of type 2 diabetes. At the same time it was common to have witnessed family members die from the disease. This resulted in a strong sense of fatalism and the belief that diabetes is a death sentence. Second, there are multiple barriers for Māori in improving health and preventing the disease. They are economic, social, cultural and institutional. As a result, depression, stress, low self-esteem and low motivation impede health behaviour change. However, the community also identified viable solutions. These included a holistic model of care, collectivist whānau based approaches, and taking small and achievable steps.

These findings were then incorporated into the documentary messaging. Community members helped determine the approach to and content of the documentary. Bandura's social cognitive theory provided a culturally sensitive theoretical basis for behaviour change in the creation of the documentary. A communications focus on whānau (family) was culturally important and positioned as a key reward to implementing health changes.

This study concludes that a CBPR approach provides an appropriate model for enacting local action-oriented approaches in the creation of a diabetes prevention documentary that reflects Māori cultural beliefs, practices, and a narrative tradition. This research contributes to the small body of international literature concentrating on the perception and lay understanding of diabetes within indigenous communities and the social and cultural meaning given to the disease. This study supports previous research that has found that CBPR is a strong model for working with indigenous populations when designing and implementing type 2 diabetes health communication materials. The application of CBPR in combination with indigenous principles provides an appropriate framework for non-Māori researchers to support culturally appropriate research that honours indigenous values and protocols.

## **Chapter I**

### **1. Introduction**

*“You see we’ve never been asked that simple question, what would we like to see in a film? We don’t get asked as Māori.”* (Māori Health Worker)

There are many persuasive statistics and studies that could be used to demonstrate why there was a compelling need to create a culturally appropriate documentary for Māori at risk for type 2 diabetes. But it is this simple statement above from a Māori health worker that is at the heart of this thesis for it begs the question why not? Over the course of the last five years I have learned that there are weaknesses in how health messages are delivered to Māori. There is a history of culturally inappropriate research methods, an over reliance on quantitative data, and a failure to employ behavioural theory or proven health communication principles. There are no published studies that explain how Māori experience and make sense of diabetes. There are no published diabetes studies that have employed social cognitive theory in message design for Māori audiences. And few studies have begun by asking the target audience not only what do they want to see, but what messages do they want to hear? In the following chapters I will document how I collaborated with Māori living in Christchurch, New Zealand to create a documentary that told the story of diabetes in the Māori community through the eyes of those who witness and experience it. In telling this story I will argue that Community Based Participatory Research provides a strong model for working with indigenous populations when designing and implementing health promotion materials.

### **2. Māori and type 2 diabetes**

Since 1990, studies have documented a sharp rise in type 2 diabetes throughout the world (Kieffer, Willis, Arellano, & Guzman, 2002). Notably, the world’s indigenous populations are overrepresented in the diabetes statistics in comparison with non-indigenous populations (Gracey & King, 2009). For example, in Australia, type 2 diabetes is more than three times more common among indigenous people than among other Australians (Diabetes, n.d.). There are multifaceted explanations given for the higher rates with indigenous populations including diet and socioeconomic factors. Environmental changes associated with the transition from traditional to westernised living and genetic predisposition have also been identified as reasons for the development of diabetes in indigenous populations (Daniel et al., 1999; Gilliland, Carter, Perez, & et al., 1998; Harris & Zinman, 2000). In New Zealand, diabetes is almost three times

more common in Māori than non-Māori. Māori are diagnosed younger and are two to three times more likely to develop complications such as eye disease, kidney failure, strokes and heart disease. Mortality rates for Māori age 45-64 with type 2 diabetes are nine times higher than for non-Māori in the same age range (Ministry of Health, 2009; Reid, 2010; Robson & Harris, 2007).

In 2010, the Canterbury District Health Board published the first comprehensive profile of Māori health in Canterbury. Data revealed that:

- From 2000 to 2005: The type 2 diabetes hospitalisation rate for Māori in Canterbury was over two and a half times higher than for non-Māori in Canterbury, while the mortality rate was more than five and a half times higher for Māori
- From 2005 to 2007: Rates of long-term complications from diabetes were two to five times higher for Māori in Canterbury than European/Others (Reid, 2010)

Ministry of Health predictions were that diabetes (diagnosed and undiagnosed) would have increased by 78% between 1996 and 2011. "The annual growth rates are 30–40% greater for Māori and Pacific than for European ethnic groups for incidence, but double for prevalence and nearly treble for diabetes-attributable mortality" (Ministry of Health, 2002, p. 25).

## **2.1 Low levels of diabetes knowledge in the Māori community**

Although these are sobering statistics, type 2 diabetes is largely preventable (Tuomilehto et al., 2001). In fact, the risk of diabetes could be reduced 50-75% by controlling obesity (especially abdominal obesity) and 30-50% by increasing physical activity (Health Funding Authority, 2002). As a result, prevention, detection and management of diabetes have become a health priority. This is a significant challenge, however, given the low level of diabetes knowledge and awareness in the Māori community. A 1993 study of Māori attitudes to diabetes in North Canterbury found that few of the fifty one participants were able to name any long term complications associated with diabetes (De Lore, Hamilton, Brown, & Lunt, 1993). Similarly, a study of forty three rural non-diabetic Māori revealed that although participants named diabetes as the number one health issue for Māori, less than one in five could identify a symptom of diabetes and less than one in three could identify a complication (Kirkwood, Simmons, Weblemoe, Voyle, & Richards, 1997). A 2003 study of an urban marae likewise found low knowledge of diabetes symptoms, complications and treatment (Simmons and Voyle, 2003).

More recently a phone survey of six hundred Māori found that almost three out of every ten Māori rated their knowledge of diabetes as 'poor' (Wyllie & MacKinlay, 2007).

### **3. Type 2 diabetes: Lack of health communication interventions with ethnic or racial minority populations**

Although the incidence of type 2 diabetes is increasing world-wide, and disproportionately affects indigenous populations, there is a notable lack of published literature discussing communication interventions designed to change behaviour in either prevention or treatment of diabetes in ethnic or racial minority populations. Because there is not a large body of work it is difficult to identify communication strategies that can be demonstrated to affect behavioural change (Institute of Medicine, 2002; Ministry of Health 2010).

In 1991, an American report found that most diabetes interventions were developed for the general population and were not culturally suitable for minority populations (Coalition for Diabetes Education and Minority Health, 1991). The following year, authors of a separate study likewise noted the paucity of research on how to meet the educational needs of minority patients with diabetes even though meta-analyses of diabetes patient education demonstrates that structured education improves patient knowledge (Brown, Duchin, & Villagomez, 1992). A decade later, an Institute of Medicine Committee report identified the same issue and the Committee suggested that diabetes provides a promising opportunity for developers of health communication interventions because unlike many chronic diseases, diabetes can be avoided or controlled with behavioural interventions (Institute of Medicine, 2002). The Committee argued that effective communication interventions are needed to address the disconnection between medical professionals' biomedical perspective on the disease and the cultural and experience based beliefs that influence how ethnic or racial minority populations experience and understand diabetes. Likewise, the American Association of Diabetes Educators (AADE) recommends respecting and incorporating lay perspectives, beliefs, and experience with diabetes rather than simply taking a conventional medical approach to diabetes education and care (Leonard, 2007).

#### **3.1 Type 2 diabetes: Identified need for culturally appropriate health communication with Māori**

Internationally few studies have focused on the perception and lay understanding of diabetes in indigenous populations or the social and cultural meanings of the disease (Boston et al., 1997). The same is true in New Zealand. And this omission is notable because as Linda Tuhiwai Smith

(2000) explained, the Māori understanding of health does not follow the Western philosophical model which distinguishes between the mental and the physical. Rather than adopting a biomedical perspective, Mason Durie conceptualises Māori health as a four-walled house describing a Whare Tapa Wha model. This Māori concept of health encompasses not only the physical (taha tinana) but is also balanced with the spiritual (taha wairua), mental (taha hinengaro) and familial (taha whanau) (Durie, 1998). For Māori, issues of Te Whenua (land), Te Reo (language) and Whanaungatanga (extended family) are central to culture and to health (Durie, 1999). I will return to the importance of this model and Māori beliefs and knowledge systems in my methodology chapter.

Several studies of Māori health identify the need for innovative models and approaches to diabetes education in order to reduce the disparities between Māori and non-Māori disease rates (Health Funding Authority, 2002; Ministry of Health, 2009; Robson & Harris, 2007). The New Zealand National Working Group on Diabetes has identified a need for culturally appropriate communication that reflects Māori beliefs and practices. Their report recommends more and better Māori specific diabetes educational resources that are appropriate and acceptable for use with the Māori community (Baxter, 2002). The low level of Māori knowledge of diabetes has been attributed to a failure to provide information that reflects Māori cultural practices in ways that are appropriate for use in Māori communities. As the Working Group notes, “Diabetes education does not always address dealing with the impact of diabetes on the lives of Māori, as Māori” (Baxter, 2002, p. 49). It has been argued that conventional approaches are insufficient when dealing with a high risk population like Māori and that more attention needs to be paid to where and how health communication is delivered (Simmons & Voyle, 2003).

Even with the best designed health communication the challenge of positively affecting health behaviour change is considerable. Effective health interventions must still motivate individuals and sustain behavioural change in eating and exercise even when the risk factors for diabetes are well known. Acknowledging both this issue and the paucity of international diabetes communication studies, the Health Funding Authority nonetheless argues for establishing community based research projects in New Zealand. It emphasises that these projects should be owned by the community and includes on-going evaluation to test interventions (Health Funding Authority, 2002).

Research problem: As the literature review will demonstrate there have been a couple of community based research studies with Māori and type 2 diabetes. However it has been impossible to ascertain what the process was for creating the resources and exactly how the

community was involved. As a result there is a gap in the literature about how to employ culturally appropriate research methods when creating health communication materials for Māori.

#### **4. Designing effective health communication interventions with ethnic or racial minority populations**

Historically, few health communication interventions have been specifically designed with culturally appropriate strategies (Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003; Marín et al., 1994). Writing in the early 1990s, Marin et al. (1994) found that health communication research focused largely on White and middle-class populations and they noted ongoing uncertainty in the health field about the need for targeted programmes for underserved populations. But they argued a consensus was also beginning to develop in the social and behavioural sciences about the need for and the necessary characteristics of group specific health interventions. They cited research on smoking, alcohol and HIV that identified behavioural differences across ethnic groups. They concluded their article by emphasising the dearth of research on effective health communication interventions for underserved populations and they made recommendations for more research to identify appropriate intervention strategies.

Kreuter et al. (2003) characterised the mid to late 1990s as a period of research that primarily focused on comparative studies of race and ethnicity and helped to establish that health promotion strategies that work with one ethnic group cannot be presumed to be as effective with others (Fabio, Regina, Rena, Christopher, & Eliseo, 1996; Kreuter, Strecher, & Glassman, 1999; Pasick, D'Onofrio, & Otero-Sabogal, 1996; Resnicow, Baranowski, Ahluwalia, & Braithwaite, 1999). Articles about cultural strategies also began to appear in popular health education text books (Pasick, 1997).

Kreuter et al. (2003) suggested that since 2000, research has moved towards developing and testing new strategies and approaches for effective interventions with racial and ethnic minority populations. More recent literature on health communication emphasises the need for increased focus on the unique characteristics of racial and ethnic groups in order to address the persistence of health disparities (House & Williams, 2000; Resnicow, Braithwaite, Dilorio, & Glanz, 2002). Noar (2006) argued that formative research is now a key component to the success of any health communication campaign. Formative research is necessary in order for designers to identify relevant behavioural determinants and health behaviour theories.

Significantly, many authors have failed to identify theory when discussing health communication interventions with ethnic or racial groups. Several studies have shown that effective health communication interventions use theory not only to develop and shape messages but to ultimately ensure behaviour change (Kennedy & Abbatangelo, 2004; Noar, 2006; Wallack & Dorfman, 2000). Further, an expert panel convened by the Centers for Disease Control and Prevention concluded that health interventions targeting a specific racial or ethnic minority group should pay particular attention to theory selection because some theories can be a poor fit with vulnerable populations (Kennedy & Abbatangelo, 2004). Randolph and Viswanath (2004) argued that one of the most critical conditions for a successful communication intervention is a comprehensive understanding of the determinants of behaviour in order to influence the behaviour. Yet in a review of articles published between 1998 and 2003 they found less than one third reported the use of a theory that informed the message production or intervention strategy. Likewise, they did not find many health interventions framing messages in culturally appropriate ways when targeting specific racial or ethnic minority populations.

Research problem: As the literature review will demonstrate the same is true in New Zealand. Of the two major diabetes campaigns with a media component, it has been impossible to definitively ascertain to what extent if any behavioural theory or health communication theory was used. Similarly, none of the produced video resources have employed behavioural theory. As a result there is a gap in the literature about how to employ behavioural theory when creating health communication materials for Māori.

## **5. Health communication, culture and ethnicity**

There is a need for health communication materials that recognise and engage with the social context that effects racial and ethnic inequalities in health (Nazroo & Williams, 2003). As Rimer and Glanz (2005) noted, there are three important reasons why culture and ethnicity are important when applying theory to a health problem: Morbidity and mortality disease rates, the prevalence of risk behaviours and determinants of health behaviours, all vary based on race and ethnicity. This argument is emphasised in a position statement on diabetes education from the American Association of Diabetes Educators (AADE). The statement outlined several possible explanations for the higher prevalence of diabetes with racial and ethnic minority populations. While they include family history and the possibility of a genetic predisposition, the statement emphasised “the complex interaction between ethnicity, socioeconomic position, gender, access to quality health care and overall health status” (Leonard, 2007, p. 41). The educators acknowledged environmental barriers, both physical and social, that work against successful

health interventions. Poor dietary choices and lack of physical activity need to be considered not just from a biomedical perspective, but also in the context of the established cultural norms in which diabetes is experienced and understood. Lack of access to cheap and healthy foods, safe places to exercise, or family and work place support, all influence “cultural norms, views and perspectives that establish rules for living that extend to cultural meaning of disease and its management” (Leonard, 2007, p. 41).

Furthermore, Kennedy and Abbatangelo (2004) noted that barriers that are of minor importance for ethnic majority audiences can become significant barriers for racial and ethnic minority populations with the greatest negative health disparities. They recommended health communication interventions and evaluations be specifically tailored from those used for majority audiences. This should include a commitment to formative research that involves members of the target audience from the outset in both programme and evaluation planning. Resnicow et al. (2002) argued that the success of health communication materials will depend on culturally relevant design that includes close attention to historical, social and environmental barriers, as well as community norms, behaviours values and beliefs.

Culture is a key element in understanding health behaviours and may impact the way a person describes and makes sense of health and disease (Gilliland et al., 1998). This is an important consideration with diabetes programmes as cultural beliefs and values powerfully influence the diet and weight behaviours of ethnic groups (Maillet, Melkus, & Spollett, 1996). In describing how most diabetes interventions may not be culturally suitable for minority populations, Gilliland et al. (1998) gave a fitting example. They noted that describing diabetes complications in the first person to a Native American may be interpreted as causing the complications to occur. In order to be effective, health interventions must take cultural context into account, which means understanding a group’s beliefs, assumptions, values and practices.

Pasick, D’Onofrio and Otero-Sabogal (1996) cautioned that it is important not to treat culture and race and ethnicity as one and the same. There are important differences both within and across different racial and ethnic groups that can be socioeconomic and educational. These differences also need to be taken into consideration when planning health communication programmes. Similarly, Linda Tuhiwai Smith (2005) argued that indigenous communities are not homogenous. Questions of power are just as pertinent with indigenous groups and issues of gender, class, language and religion can all empower some and silence others.



## 5.1 Cultural sensitivity and health promotion strategies

Resnicow, Baranowski, Ahluwalia, and Braithwaite (1999) agree that ethnic groups face barriers to care that are both socioeconomic and cultural and that cultural sensitivity needs to be shown in gathering information. However, they noted that while cultural sensitivity is a widely accepted principle, it has no commonly cited definition. They define it as

The extent to which ethnic or cultural characteristics, experiences, norms, values, behaviour patterns, and beliefs of a target population, and relevant historical, environmental, and social forces are incorporated in the design, delivery and evaluation of targeted health interventions, including behavioural change materials and programs.  
(Resnicow et al., 1999, p.11)

They proposed that cultural sensitivity has two dimensions—*surface structure* and *deep structure*. Surface structure comprises matching intervention materials and messages to observable characteristics of a population. With print and audio visual materials this might mean using people, music or locations familiar to the target audience. Whereas surface structure refers to the extent to which interventions fit with the culture and behavioural patterns of the target population, deep structure considers how a variety of complex factors (cultural, social, psychological, environmental, historical) influence the health behaviour of the target population and their understanding of the target behaviour. For this reason, “Whereas surface structure generally increases the receptivity or acceptance of messages, deep structure conveys *salience*. Surface structure establishes the feasibility and acceptance of an intervention, whereas deep structure is believed to contribute to program impact” (Resnicow et al., 2002, p 495).

Building on this argument, Kreuter et al. (2003) identify five main categories that health promotion practitioners now use to make programs culturally appropriate.

- Peripheral strategies describe the “surface structure” characteristics of materials or programs. For example, a clear use of colours, images and pictures that immediately resonate with a particular group.
- Evidential strategies attempt to heighten the perceived importance of a health issue by presenting specific evidence of its impact, most commonly through the presentation of epidemiological data.
- Linguistic strategies translate program information from one language to another.

- Constituent-involving strategies follow a philosophy of community participation which includes significant input from community members in planning and decision making.
- Sociocultural strategies reflect the “deep structure” characteristics of cultural sensitivity where a group’s “cultural values, beliefs and behaviours are recognized, reinforced, and built upon to provide context and meaning to information and messages about a given health problem or behaviour” (Kreuter et al., 2003, p 136).

Some of these strategies have been employed with previous health communication initiatives about type 2 diabetes that targeted Māori. In the following chapter I will critically review these initiatives and make the argument that community based participatory research (CBPR) encompassing constituent-involving and sociocultural strategies is a fitting methodological approach for health initiatives with Māori.

## **6. Community Based Participatory Research (CBPR) and digital communication**

Research problem: There is a clear and identified need for innovative approaches to diabetes education and prevention that reflect Māori cultural practices in ways that are appropriate for use in Māori communities. One of the noted strengths of the Community Based Participatory Research process is that it can result in the production of non-academic resources like documentary which challenge the academic framing of others people’s words (Wallerstein & Duran, 2006). Notably there have been only a few video/digital resources about diabetes produced for Māori even though Ministry of Health reports support their use as an effective educational tool (Ministry of Health, 1994; Public Health Commission, 1997). This is surprising because digital communication has the potential to be a culturally sensitive form of communication for Māori who have a strong oral storytelling culture (Bishop, 1996). However, as will be further explained in the literature review there is a lack of studies demonstrating that a specific type of communication can facilitate behavioural change. There is some evidence that video education can increase diabetes knowledge and that social modelling can facilitate learning (Dyson, Beatty, & Matthews, 2010; Tuong, Larsen, & Armstrong, 2012).

### **6.1 Why CBPR is a good fit with Māori**

A tenet of effective health communication design is that planners need to frame messages in culturally appropriate ways which means targeting and tailoring media programmes (Kennedy & Abbatangelo, 2004; Resnicow et al., 2002). The CBPR approach is appropriate because intervention strategies designed following its principles will reflect the cultural values,

behavioural preferences, expectations and environmental context of the participating community (Kieffer et al., 2004). CBPR has been successfully implemented with health work in indigenous populations notably in developing culturally competent interventions with Native American tribes in the United States and Canada (Burhansstipanov, Christopher, & Schumacher, 2005; Christopher, Watts, McCormick, & Young, 2008; Holkup, Tripp-Reimer, Salois, & Weinert, 2004; Horn, McCracken, Dino, & Brayboy, 2008; LaVeaux & Christopher, 2009; Strickland; Walters et al., 2009) and with Aboriginal women in Australia (Green & Dickson, 2001; McHugh & Kowalski, 2009).

Both researchers designing media campaigns and researchers designing public health programmes have called for increased sensitivity to diverse cultures and minority audiences when planning health education programmes (Marin et al., 1994; McLeroy et al., 1995; Resnicow et al., 2002; Vega, 1992). Health programmes for Māori must take into account the impact of colonisation on Māori health. As Voyle and Simmons (1999) outlined, alienation and marginalisation have had disastrous consequences for identity, cultural tradition, social cohesion, self-esteem and economic survival. Consequently morbidity and mortality data for Māori and other indigenous populations are far higher in comparison with non-indigenous populations. As outlined in the literature review, CBPR is rooted in an approach that acknowledges that inequities in health status are part of a complex social, political and economic system that includes factors such as poverty, racism, housing and employment (Israel et al., 2005, Israel et al., 1998). Furthermore, it will be demonstrated that CBPR is a good fit and an appropriate approach for conducting research with Māori particularly within a framework that incorporates indigenous principles (Mohammed, Walters, LaMarr, Evans-Campbell, & Fryberg, 2012).

## **7. Research objective:**

The focus of this thesis is to ascertain how Community Based Participatory Research (CBPR) in combination with proven health communication principles and behavioural theory can be employed to create an appropriate resource for Christchurch adult Māori at risk for type 2 diabetes.

I will outline and describe the community development process of working with an indigenous population to develop a health communication resource that reflects Māori beliefs and cultural practices.

**Research question:**

How can CBPR and behavioural theory best be employed to create a culturally relevant digital media resource for adult Māori at risk for type 2 diabetes?

**8. Thesis overview**

In the next chapter I will provide a critical review of health promotion literature in order to demonstrate why there is a need for both a community based participatory approach and the application of behavioural theory when creating diabetes resources for Māori. I will begin with an overview of the limitations of epidemiological data and then focus on what lessons can be learned from social marketing that can inform better health communication strategies with Māori. I will discuss the use of video as a health promotion resource and critique the literature on CBPR interventions for the prevention of type 2 diabetes. The chapter will conclude by showing that there are clear research gaps and that there is a need for a digital diabetes prevention resource that employs a community based approach and behavioural theory in the shaping of a culturally relevant narrative.

The following methodology chapter will focus on the CBPR model with a discussion of its historical development and epistemological traditions. I will discuss the similarities as well as the differences with Kaupapa Māori research. In the second part of the chapter I will outline my research design and methods with particular attention to indigenous research principles. In doing so I will present an argument to employ a specific set of evaluation criteria for CBPR projects.

The results chapter will detail the research process that informed the content and production of the documentary. It will begin with a description of the partnership development process. The importance of spending time in and gaining the trust of the community are detailed and there is a discussion of the role of the researcher in developing advisory groups. This is followed by a specific explanation of how the Community Advisory Board (CAB) was formed. The following two chapters describe the analysis of the qualitative data generated by key informant interviews and hui (focus groups). Particular attention is paid to key themes and how they informed the documentary messaging.

The following chapter on documentary production will explain how the major findings from the key informant interviews and hui discussions informed the content and messaging of the documentary resource. I detail how the knowledge, attitude and behaviour change goals were formalised and describe the results of an additional hui held to refine the approach. The second

half of the chapter is devoted to the production of the documentary resource with particular attention paid to the application of social cognitive theory. Relevant examples are given and the reader is directed to the full script and an online link to the completed resource. I make the argument that in employing behavioural theory I addressed a gap in the existing research, namely the failure of previous diabetes initiatives to employ behavioural theory in the shaping of messaging for Māori audiences.

The penultimate chapter describes the process evaluation. I discuss the reasons why a process evaluation was an integral part of this study. I first offer a brief recap of the study's purpose, why CBPR was employed, and some of the identified research gaps I hoped to address. I then go on to demonstrate through a discussion of eight indigenist principles, how my research engaged the community in the co-production of a culturally appropriate diabetes prevention documentary.

Finally, the concluding chapter discuss lessons learned; the strengths and weaknesses of the research with recommendations for future research that might prove useful to other researchers contemplating CBPR projects with Māori. The thesis concludes with some practical policy recommendations informed by my research findings.

## **Chapter II. Literature Review**

### **Chapter overview**

The aim of this chapter is to provide a critical review of health promotion literature in order to demonstrate why there is a need for both a community based participatory approach and the application of behavioural theory when creating diabetes resources for Māori.

The chapter is divided into three major sections. The subject of the first section is an overview of the limitations of epidemiological studies and a review of major mass media health promotion campaigns in New Zealand that have targeted a Māori audience. I will focus on what lessons can be learned that can inform better health is a communication strategies with Māori.

Next I will discuss The *Ngati and Healthy* project, a community based initiative in the east coast region of New Zealand designed to tackle the increase in type 2 diabetes. Strengths of the community process will be highlighted. However, limitations will be identified that make it difficult to draw conclusive lessons or to understand specific processes that might prove helpful for designing culturally appropriate health communication resources.

The second part of the chapter will concentrate on the use of video as a health promotion resource. It will include a review of the limited literature on the efficacy of video. I will critique the existing video resources on diabetes prevention for Māori and argue that there remains an identifiable need for a culturally appropriate digital diabetes resource.

The final section of the chapter is devoted to critiquing the literature on Community Based Participatory Research (CBPR) interventions for the prevention of type 2 diabetes. After discussing international and domestic examples, I will draw attention to the limited but pertinent studies that have specifically employed participatory research approaches in the creation of stand-alone health promotion videos.

The chapter will conclude by showing that there are clear research gaps and that there is a need for a digital diabetes prevention resource that employs a community based approach and behavioural theory in the shaping of a culturally relevant narrative.

### **9. Epidemiological studies**

Epidemiological Studies examining the disparities between Māori and non-Māori disease rates are critical in helping researchers understand the cause of type 2 diabetes (Reid, Robson & Jones,

2000). The development and evaluation of diabetes interventions provides policy makers, health service providers and indigenous communities with valuable data to improve health outcomes related to the disease (McNamara, Sanson-Fisher, D'Este & Eades, 2011).

However, a 2011 study that evaluated the quantity and methodological quality of intervention research on diabetes in indigenous populations (including New Zealand) found that only twenty five percent of the studies published between 1989 and 2008 met the criteria for methodological quality (McNamara et al., 2011). The authors suggested that ethical and methodological issues may have contributed to the lack of high quality intervention research. For example, the ethics of control groups and randomisation can be problematic because many indigenous communities object to withholding a potentially helpful intervention to some members of the community. In addition, contamination between the control and intervention groups is more likely in an indigenous setting where extended family and kinship systems can result in greater contact between intervention and control participants. This issue was identified by Blundell, Gibbons and Lillis (2010) in their review of the challenges of a community base diabetes intervention in New Zealand. They noted that contamination was inevitable given that control and intervention groups were defined by location rather than social or whānau connections. While this contamination would comprise research findings, they argued that it is culturally appropriate and an ethical necessity. Failure to acknowledge genealogical links and kinship would comprise Maori tikanga (protocol).

As the creation of a culturally relevant and appropriate digital media resource is the desired outcome for my study then the sociocultural context in which diabetes is experienced first needs to be understood. Lambert and McKevitt (2002) argued that while descriptive epidemiology is useful, quantitative analysis alone is not enough to describe and characterise a community's health. Similarly Montoya and Kent (2011) found that while surveys and clinical data can help researchers to learn about individuals, qualitative research provides a broader picture of a community's experiences with both their historical and current conditions. While quantitative data provides helpful information about cause, epidemiological studies do not explain how Māori understand and make sense of the disease. These studies and other clinical data also fail to provide a critique of the impact that non-Māori systems, ideologies and colonial practices have had on Māori ill health (Cram, McCreanor, Smith, Nairn, & Johnstone, 2006). Persistent inequities in health are the result of long standing historical, economic and political conditions (Durie, 2001). Other researchers have cautioned that focusing solely on epidemiological statistics to highlight health inequities can perpetuate a view of indigenous communities as sick and

dependent (Browne, Smye & Varcoe, 2005; O'Neil, Reading, & Leader, 1998). This is important because as Cram et al. (2006) found Māori patients and non-Māori doctors have very different ways of talking about health. Qualitative interviews with doctors revealed that they explained health disparities in conventional biomedical terms with no acknowledgment of factors such as the impact of colonialism or racism.

Epidemiological studies and clinical data do not explain how social or cultural factors might also contribute to health status. For example, Māori have a different conception of body image and obesity and have not responded well to emphasis only on physical health (Blundell et al., 2010). Blundell et al. (2010) have criticised previous research for neglecting to include the concept of Te Wairua Māori (spiritual wellbeing). They argued that this omission has created a false impression of Maori as being solely responsible for their own poor health. This is important because as Browne et al. (2005) caution, the dominance of epidemiological discourses creates what O'Neil et al. (1998) describe as “systems of surveillance” that shape the public understanding of indigenous people and communities.

As outlined in the introductory chapter, there is a need for health communication materials that recognise and engage with the social context that effect racial and ethnic inequalities in health (Nazroo and Williams, 2003). There is also an identified need for culturally appropriate communication about type 2 diabetes that reflects Māori beliefs and practices (Baxter, 2002). And significantly, there are low levels of diabetes knowledge and awareness in the community. This would suggest that while the extent of the diabetes problem in the community has been clearly identified this has not translated into appropriate health communication.

## **10. Health promotion campaigns**

Some key lessons about how to convey health messages to Māori communities can be garnered from a review of mass media health promotions in New Zealand. However it is important to note that all of the campaigns discussed below had multiple media components (television commercials, print, radio and in one case documentary) and employed multiple intervention strategies. As a result, this makes evaluation problematic and it can be difficult to ascertain which strategy or communication channel was most effective (Thornley, Waa and Ball, 2007).

### **10.1 ‘It’s about whānau’ smoking cessation media campaign**

The ‘It’s about whānau’ campaign launched in 2001 with the aim of encouraging Māori to quit smoking. Fifteen television commercials were produced with accompanying print and radio



advertisements. Cross section surveys were conducted to measure recall, awareness perception and behaviour change. Over fifty percent of Māori smokers said that the campaign had made them more likely to quit. A similar percentage rated the commercials believable and relevant (2008). There are several pertinent reasons why this campaign was judged successful. First, the theoretical framework was culturally appropriate and utilised the Te Whare Tapa Wha Māori health model (Durie, 1998). The campaign focused on one of the four elements of the model- whānau (extended family). As the designers of the campaign explained, whānau plays a dualistic role. Not only does it suggest a supportive environment for the smoker to quit, it also conveys a reciprocal obligation on the part of the smoker to change to support their whānau members (Grigg, Waa and Bradbrook, 2008). Second, in-depth qualitative interviews helped inform message design. For example, many interviewees were concerned about overly negative stereotyping. Therefore a decision was made to avoid overt threat appeals and emphasise positive empowering messages. Finally the commercials featured real smokers and their whānau discussing quitting. As a result they were rated as believable.

## **10.2 National Cervical Screening Programme**

This project aimed to increase participation by Māori and Pacific women in the National Cervical Screening Programme (NCSP) using a social marketing approach. The advertising campaign was just one element of a broad programme which included improving access to services, better service delivery, updated educational resources as well as workforce development (Bethune & Lewis, 2009). Again valuable lessons can be learnt from how the research was used to inform the development of the national communications campaign. In-depth interviews and focus groups led by Māori and Pacific interviewers, as well as structured interviews with community leaders provided valuable insights into barriers and facilitators for screening. These insights informed the creative strategy. Women wanted compelling real life stories and the use of humour, both of which were incorporated into eight television commercials, radio, outdoor and other advertising material (Bethune & Lewis, 2009). The resulting campaign received good cut through with the audience. In a post campaign survey conducted a year after launch, key campaign messages were recalled by seventy five percent of the target audience. The likelihood of their being screened also increased by forty nine percent (Bethune & Lewis, 2009).

### **10.3 One Heart Many Lives**

One Heart Many Lives (OHML) was a national primary prevention programme sponsored by PHARMAC (Pharmaceutical Management Agency) that aimed to reduce the risk of cardiovascular disease in Māori and Pacific men. Like the NCSP programme discussed above, OHML targeted multiple levels of the health sector. Initiatives included television commercials, radio, print, web and community events. While it was a national programme what made it distinct was community involvement at a regional level. There was an emphasis on the development of local initiatives, for example providing free heart checks at a cultural festival (Penney & Fieldhouse, 2012). Evaluations of regional campaigns were completed but despite repeated requests I have been unable to acquire them directly from PHARMAC. Secondary analysis notes some successes but did not specify between national marketing (e.g. television commercials) and local community driven initiatives (Leow et al., 2011). Two of the key strengths identified by a 2008 evaluation are of interest. Each District Health Board tailored the programme to the region and ensured it was community driven and community owned. And a key element was identifying local heroes who could serve as positive role models and encourage others to make changes (Wilson, 2008 as cited in Leow et al., 2011). For example, in the Northland region a magazine resource (The Bro Files) was developed that contained stories of local men making changes to their health. A documentary DVD was also produced by PHARMAC that told the story of two of these men. Unfortunately despite numerous attempts I have been unable to acquire any additional information about how the documentary was utilised or whether its effectiveness was ever evaluated. Thornley et al. (2007) have summarised the key lessons learned from campaigns with Māori. They include early engagement with the community and key stakeholders, involvement of Māori in planning and development, and the use of culturally appropriate processes. The following critique will illuminate similar strengths but also notable shortcomings in a programme to prevent type 2 diabetes.

### **10.4 Let's Beat Diabetes: Overview**

Let's Beat Diabetes (LBD) was a comprehensive five year plan to prevent and manage type 2 diabetes. It had an allocated budget of approximately ten million dollars, funded primarily by Counties Manukau District Health Board. The campaign's target audience was geographic (Counties Manukau, Auckland), with a significant focus on Māori and Pacific people. The stated aim of the programme was "to prevent or delay the onset of type 2 diabetes, slow disease progression, and improve the quality of life for people with diabetes in Counties Manukau" (Counties Manukau DHB, 2005, p.32). The campaign utilised a wide range of strategies from the

“whole society, whole life course, whole family” approach originally developed by the United States Center for Disease Control. This strategic approach acknowledges that positive health change requires community, institutional, and family support, as well as primary health intervention (Counties Manukau DHB, 2005). The five year plan document had the goal of changing societal norms to obesity and diabetes. In order to change environments and behaviours the health board outlined a campaign plan to simultaneously target government, industry, community, family and individuals. The programme went on to fund a professionally designed advertising strategy with the goal of changing knowledge, attitudes and behaviours towards nutrition and physical activity (Counties Manukau DHB, 2005).

#### **10.4.1 Let’s Beat Diabetes: Marketing campaign**

The general campaign had two phases. Phase one launched on 18<sup>th</sup> June 2007, employed the phrase “Swap2Win” and had two marketing objectives. The first, to get families moving more and the second, to get families to adopt a healthier diet. In keeping with a social marketing approach the rationale was to both promote and facilitate behaviour change (Waldron, 2007). The promoted brand message was “Together We Can Stop Obesity,” and the goal was to be positive and focused on the need for collective action. In order to promote behaviour change, healthy behaviour tips were promoted based on four behavioural outcomes (reducing sugar, fat, portion control and increasing movement). Decisions about the specific swap messages were made with two key LBD criteria in mind—the likely health impact of the swap and the likelihood of the swap being adopted (G. Waldron, personal communication, October 31, 2013). These messages were promoted through a variety of paid and free media channels including mail drops, local newspapers, billboards, radio, and healthcare networks.

In order to facilitate behaviour change the campaign designers created testimonial advertisements profiling four local groups as role models who had accepted the Swap2Win challenge. One group was from the Franklin Marae. The desired outcome was a domino effect with the profiled groups influencing others to adopt similar healthy behaviours (Waldron, 2007). These messages were promoted through several community newspapers. Swap2Win advertisements also ran in selected community newspapers and on five local radio stations. The emphasis was on small steps and simple changes (for example, switching from full fat to low-fat milk). Swap2Win booklets and posters were also distributed free to every home in the Counties Manukau District Health Board area and to a variety of organisations including Primary Health Organisations and Community Health Services.

#### **10.4.2 Process and outcome evaluation: Swap2Win**

In 2008, Auckland University scholars at the Centre for Health Services, Research and Policy released a detailed process and outcome evaluation of the Swap2Win campaign (McNeill, Clinton, Brown, & Appleton, 2008). The report highlighted campaign successes but also drew attention to several shortcomings that are particularly relevant to designing health promotion initiatives with racial and ethnic groups. Notably the report's authors documented shortcomings in the consultation process that had implications for formative research, theory selection, audience segmentation and message appropriateness.

In 2007, a benchmark survey was conducted for the LBD campaign to ascertain the target community's understanding of diabetes. Phone interviews were completed with Counties Manukau residents including 594 Māori participants randomly selected from the White Pages. The analyses were based on all persons who included Māori as one of their ethnic groups. Survey results demonstrated that there was a lack of knowledge about diabetes, including a lack of awareness of cause or that it can be prevented, delayed or managed (Wyllie & MacKinlay, 2007). However, the results of this survey were published after the campaign was underway and as a result, the findings were not used in the development of marketing materials that responded to local values, needs or knowledge (McNeill et al., 2008, p.41). This oversight is significant because as previously discussed in the introductory chapter, formative research is a key component to the success of any health promotion campaign. Formative research is necessary in order for health promotion designers to identify relevant behavioural determinants and health behaviour theories (Noar 2006). Notably, even if the survey results had been published in time the survey data itself contained little information about behavioural determinants (McNeill et al., 2008, p. 87).

#### **10.4.3 Campaign messaging: Cultural insensitivity and lack of pre-testing**

Qualitative consumer research was conducted prior to the survey and was used to identify a strategic approach for the campaign. It is reasonable to assume this research was conducted by the two commissioned advertising agencies in consultation with the LBD Social Marketing Project Manager. The LBD report does not detail how Māori were included in this phase of the campaign development although key stakeholder feedback to the evaluation researchers suggested there were significant shortcomings that had a knock on effect as the campaign strategy developed. The first set of images and strap lines developed by the advertising agency were based on fighting and violence with the strap line "Obesity-it's a fight we can win"

(McNeill et al., 2008, p.46). One of the print advertisements developed showed a parent in boxing gloves standing above a child at a dinner table. The implication was that the child should eat the healthy food prepared for them. The image encountered strong disapproval from a number of community partners who pointed to the cultural insensitivity of the correlation with domestic abuse in the Counties Manukau area (K. Pickering, personal communication, September 10, 2013). When community partners objected they were told that the advertising agency did not want to change the print advertising because the message would not be as effective (McNeill et al., 2008, p. 46). While the boxing gloves theme was eventually replaced, McNeill et al. describe how this decision had long term implications for the effectiveness of the overall campaign. With the original completion timeline pushed back, decisions about campaign messages were then made by the LBD steering group and messages were not tested with any of the target groups.

#### **10.4.4 Lack of culturally tailored messaging**

Another key finding of the report was that the campaign primarily took an inclusive approach and was designed to facilitate behaviour change in the whole Counties Manukau population. Key stakeholder interviews suggested that a segmented approach specifically targeting Māori and Pacific audiences would have been more appropriate with messages tailored to the target group's experiences, values and needs. This feedback is supported by the academic literature discussed in the introductory chapter. The New Zealand National Working Group on Diabetes has identified a need for culturally appropriate communication that reflects Māori beliefs and practices and the low level of Māori knowledge of diabetes has been attributed to a failure to provide information that reflects Māori cultural practices in ways that are appropriate for use in Māori communities (Baxter 2002). Further, literature on health communication emphasises the need for increased focus on the unique characteristics of racial and ethnic groups in order to address the persistence of health disparities (House & Williams, 2000; Resnicow et al., 2002). And as previously discussed, there is a need for health communication materials that are culturally sensitive and recognise and engage with the social context that effects racial and ethnic inequalities in health (Nazroo & Williams, 2003).

The evaluation of the design of the campaign's messages revealed both successes and failures. Key stakeholders spoke positively about the focus on images rather than words, simple practical swap tips, and the inclusion of local role models as a way to empower local communities to engage in similar behaviours. McNeill et al. found that some of the stakeholders found the Swap2Win message confusing as it was not made explicit what the tangible benefits of adapting

the healthy behaviour were (McNeill et al., 2008, p.76). An outcome evaluation survey that used a computer assisted telephone interview was also completed after the campaign ended in September 2007. As described in the evaluation report, the Telecom residential listings were used to randomly sample four hundred residents, sixteen years or older, from within Counties Manukau. A disproportional stratified sample was obtained to provide adequate samples of Māori, Pacific and Asian participants for the presentation of meaningful results from these subgroups. The survey results indicated that participants had become more concerned about obesity and were more motivated to eat healthily. The majority of the study population that were aware of the Swap2Win campaign indicated that they did not become more active in any way after hearing about the campaign (McNeill et al., 2008, p. 7).

In conclusion Mc Neill et al. made a number of recommendations including earlier community consultation and increased and special consideration for consultation with Māori and Pasifika. They also advised that future campaigns should be based on the target audience's experiences, values and needs in order to understand behaviour and encourage behaviour change. This would necessitate focus groups rather than survey data and pre-testing of campaigns with the target audience (McNeill et al., 2008, p. 87). This would also require messages to be culturally tailored. As a similar process evaluation has not been located for phase two it has been impossible to determine whether consultation improved and the report's recommendations were followed.

#### **10.4.5 Phase two communications evaluation:**

A report later commissioned to evaluate the effectiveness of phase two of the campaign determined that the main shortcoming of the phase one Swap2Win strategy was that it did not address, and therefore did not answer, the question of why people needed to change. It also focused on obesity rather than diabetes (Wyllie, 2009). Hence phase two focused on the production of twelve additional advertisements to generate the knowledge and momentum to better prevent, delay or manage diabetes. The campaign utilised psychographic modelling which looks at how communities are clustered together by values. The visual and verbal messages were then crafted to reflect these values (Counties Manukau DHB, 2009). Three of the print advertisements showed the consequences of diabetes (dialysis, amputation and blindness) with the strap line 'It doesn't have to be this way.' The remaining print advertisements focused on ways to reduce the risk of getting diabetes. All of the print ads had a header DIABETES in large bold font.

An evaluation of the advertising campaign was conducted in 2009. This report was commissioned by Counties Manukau DHB and conducted by a commercial company. It was based on two Computer Assisted Telephone Surveys that questioned participants about their recall of the ads and their possible changes in attitude as a result of exposure to the campaign. The report's author concluded that it was a highly effective campaign with levels of recall comparable to other big budget national campaigns. Fifty one percent of people surveyed had discussed the ads at least once, and a similar number, 52%, rated the advertisements as relevant to them (Wyllie, 2009). Yet survey results indicate that when questioned, respondents identified the main source of their information as television even though it was not used as a channel for advertising. In addition, because of the identified low levels of health literacy among the campaigns target audience (including Māori) LBD planners cautioned that the inconsistent messages evident in more general media coverage of health might have undermined the strength of the campaign messages (Paraone, Barron, Walker and Sinclair 2009). The evaluation also found an increased awareness of the connection between a healthy diet and the prevention of diabetes. The author of the evaluation report noted that the results might have been influenced by other health campaigns running concurrent with the diabetes initiative, but he concluded that the key point about the LBD campaign was that its messages were explicitly linked to diabetes and that it took this campaign to achieve it (Wyllie, 2009).

The evaluation survey indicated that the campaign was influencing attitudes with 72% of Māori surveyed stating they were now more concerned about obesity and 84% that they were more concerned about diabetes (Wyllie 2009). A comparison of two population surveys revealed that the campaign was most successful in building awareness about the linkage between healthy diet and the prevention of diabetes. Māori participants indicated increased concern about health problems resulting from being overweight and that someone they know had or might get diabetes (Paraone et al., 2009). While acknowledging the successes of the campaign, a final evaluation also noted some disappointing results. There was no movement in the target audience's knowledge and awareness of the association between reducing fat intake or portion size and maintaining a healthy weight. Likewise, there was no association between being active and maintaining a healthy weight and preventing type 2 diabetes. Moreover, there was no reported increase in people wishing to be active (Paraone et al., 2009)

#### **10.4.6 Summary of lessons learned from marketing campaigns with Māori**

In summary this section of the literature confirms that the foundation for successful behaviour change messaging with Māori is a culturally appropriate theoretical framework and a clearly

identified health behaviour theory. Furthermore, early and ongoing engagement with key stakeholders is critical. Community driven initiatives can be more responsive to local concerns and ensure buy in. In-depth qualitative interviewing and culturally appropriate processes are important for identifying relevant behavioural determinants. In addition, messages should be culturally tailored and be created in response to community knowledge, experiences, needs or values.

All of the campaigns discussed above had resources, considerable expertise and funding to draw on. Time frames for development were reasonably long, there was a budget for a media spend for print, radio, broadcast and billboards, and the campaigns had regional or national reach. They also employed multiple intervention strategies as part of a broader social marketing campaign. Obviously these resources are not available to a majority of community groups or health organisations looking to affect positive health behaviour change in their community. For this reason, the following discussion will focus on a community based approach to diabetes prevention. In the introductory chapter I argued that a CBPR approach is appropriate because intervention strategies designed following its principles will reflect the cultural values, behavioural preferences, expectations and environmental context of the participating community (Kieffer et al., 2004). A review of the following project can offer further lessons on how to create an appropriate resource for Māori at risk for type 2 diabetes.

## **11. Ngati and Healthy Prevent Diabetes Project**

The Ngati and Healthy project was initiated by the Ngati Porou Iwi who challenged the community owned health care provider, Ngati Porou Hauora, to tackle the increase in type 2 diabetes in the community. This led to the development of a partnership with academic researchers at the Edgar National Centre for Diabetes Research at the University of Otago. The project was designed to utilise what the researchers describe as a *participatory community development model* in an attempt to translate clinical evidence into a community setting. The researchers' premise was that although clinical evidence demonstrates that type 2 diabetes can be prevented through lifestyle change, the critical question remains how to successfully implement and translate this knowledge into a public health programme (Tipene-Leach et al., 2013).

A paper on this study described steps taken that are consistent with a participatory community model (Tipene-Leach et al., 2013). Time was spent developing trust between the participating academics, health providers and community members. Emphasis was placed on community engagement and ownership to increase both the relevance and the acceptance of the project. The



researchers followed Netto et al.'s five principles for the design of health promotion initiatives for minority groups (Netto, Bhopal, Lederle, Khatoon, & Jackson, 2010). First, they specified the use of community resources to ensure accessibility to intervention activities. Second, they talked with the community to identify potential barriers to change. Third, they discussed with the community how health messages should be implemented and delivered. Fourth, the research team's guiding principles were formulated by team members from the community who understood local values and networks. Fifth, they utilised community health workers who had both understanding and access to community members in geographically isolated locations. As evaluations of OHML found, it is important to recognise that communities are unique and these unique features should influence how interventions are developed and implemented. Precisely because the style and delivery of interventions should be shaped and determined by the needs of the community, generalisability will always be compromised. As Tipene-Leach et al. (2013) observe, the intervention principles may be the same but the intervention 'product' will be different.

The intervention was designed with three main components: The community education component included activities like cooking demonstrations and the structural strategy included attempts to target school nutrition. The third component was health promotion initiatives conveying healthy lifestyle messages. The health promotion strategy began with a baseline prevalence survey. Three hundred and seventy one randomly selected participants and volunteers (adults twenty four years and older) completed a lifestyle and dietary behaviour questionnaire and a glucose tolerance test. The questionnaire was designed to obtain demographic information, medical history and limited information about exercise and dietary practices. The questions selected had previously been used in other national surveys. The questions about exercise were adapted from the 1996/1997 NZ Health Survey Adult Questionnaire and the questions about diet were selected from the 1997 NZ National Nutrition Study. Analysis of the clinical variables and survey results found that regular physical activity, defined as five times a week for at least 150 minutes, was associated with an approximate halving of the risk of being insulin resistant or having the metabolic criteria for the diagnosis of type 2 diabetes. A similar result was found for those participants who had a high intake of dietary fibre from fibre rich foods, whole grains and fruits and vegetables (Mann et al., 2006).

The results informed three key communication messages: To increase consumption of fruit and vegetables; to increase consumption of wholegrain foods and three; to increase exercise levels (Tipene-Leach et al., 2013). What Kreuter et al., (2003) would call a *constituent involving*

*strategy* was then employed. Discussions among the research team and community members formalised how to translate these messages in a culturally appropriate way. Discussion also helped to identify important themes and principles. For example, there was agreement that media initiatives reflect the ethos of the local population and be recognisably Ngati Porou. Likewise, messages needed to be positive and affirming rather than negatively berating the community. Radio advertisements and jingles, posters and exercise training cards were then created by a NPH diabetes nurse and tribal member.

## **12. Limitations**

Limitations on reporting make it difficult to draw conclusive lessons or to understand specific processes that might prove helpful for designing culturally appropriate health promotion resources for Māori. Although community input was clearly sought and was critical to the ongoing relevance and acceptance of the project, neither behavioural change theory nor health communication principles were employed in the crafting of the messages (K. Coppel, personal communication, September 18, 2013). As previously noted, one of the most critical conditions for a successful communication intervention is an understanding of the determinants of behaviour in order to influence the behaviour (Randolph and Viswanath, 2004). Further, it is not clear from the published research exactly what the process was for formally soliciting and incorporating community input and no process evaluation has been published. Therefore, it cannot be determined how many people were talked to, what they were specifically asked about, or how this information was then analysed. Tipene Leach et al. (2013) wrote that there was a need for different communications channels for different sectors of the community but unfortunately do not expand on this and explain why. Despite several attempts, I was not able to acquire copies of any of the media generated for the campaign. Furthermore, evaluations were conducted by private companies rather than led by the research team. Again this data has not been published. Finally, the survey data that informed the health messaging was epidemiological information and did not survey the target audiences knowledge or understanding of diabetes. As a result the researchers did not acquire information about the target audience's experiences, values and needs which is necessary to understand behaviour and encourage behaviour change (McNeill et al., 2008, Noar 2006).

In the preceding sections of this chapter the literature on health promotion with Māori was synthesised in order to understand what lessons could be learned about how to create culturally appropriate health promotion resources. The discussion of Ngati and Healthy adds to this by emphasising the importance of community involvement to ensure relevance and acceptance. In

the following section I will outline an argument for utilising video as an appropriate medium to convey health information.

### **13. Health literacy and Māori**

The *Healthy People 2020* report defined health literacy as “the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.” (US Department of Health & Human Services, 2010). Low literacy skills can impede effective health communication as individuals who cannot understand health messages cannot act upon them. As Dollahite, Thompson and McNew (1996) have argued, while knowledge alone does not lead to behaviour change, it is a prerequisite to getting people to consider changing unhealthy behaviours. In New Zealand, the 2006 Adult Literacy and Life Skills Survey (ALL), revealed that seventy percent of Māori do not reach the minimum literacy skills level required to read document (Ministry of Health, 2010). A Ministry of Health report, *Korero Marama: Health Literacy and Māori*, sourced data from the health-related questions in the 2006 ALL survey to measure the health literacy skill level of the New Zealand population. The research team found that on average, New Zealanders have poor health literacy skills, with both Māori and non-Māori males and females scoring on average less than 275, which using the Australian Bureau of Statistics model is the minimum score required for individuals to meet the complex demands of everyday life and work in a knowledge-based economy. Moreover, Māori have much poorer health literacy skills compared to Non-Māori regardless of gender, age, education, income, labour force status or rural/urban location. Eighty percent of Māori males and 75% of Māori females were identified as having poor health literacy skills (Ministry of Health, 2010).

Given the low levels of Māori health literacy it is notable that neither Ngati and Healthy or Let's Beat Diabetes employed digital video to verbally or visually communicate health messages to their Māori audiences. Moreover, there have only been a few video/digital resources about diabetes produced for Māori even though Ministry of Health reports support their use as an effective educational tool (Ministry of Health, 1994). As a means of conveying health information, video offers several possible advantages over print materials. People can be shown demonstrating the desired behaviour (video modelling). Health promoters can present the behaviour as pertinent to real-life circumstances rather than in the abstract and present the behaviour as enjoying the approval and support of the community (Flay & Burton, 1990). Likewise, some studies have shown that culturally sensitive videos have been effective at influencing behavioural change (Solmon & Dejong, 1988; Yancey, Tanjasiri, Klein, & Tunder, 1995). Yancey et al. (1995) found the screening of a culturally sensitive documentary video

significantly increased cervical cancer screening behaviour with African American and Latino women. The study utilised focus groups with the target audience where they were asked open ended questions about barriers to screening. There was a particular focus on attitudinal barriers related to cultural values. Short documentaries were then created that included interviews with patients that explored fears, feelings and misconceptions about screening. A second video contained prevention messages. Videos were then screened in health clinic waiting areas. At one control site the number of requested cervical screenings doubled in the four month interval following the airing. The authors concluded that the audio-visual medium allows recommended health behaviours to be modelled in culturally appropriate and cost effective ways (Yancey et al., 1995; Yancey & Walden, 1994).

### **13.1 Video as a medium for health promotion**

Ascertaining the strengths and weaknesses of video as channel of health communication relative to other forms of communication is difficult due to gaps in the existing literature. Gagliano's (1988) literature review on the efficacy of video for patient education analysed twenty five video studies, the majority of which were randomised controlled clinical trials. While the review is dated, it is still useful because the author specifically assessed the effect of video alone. However, it should be noted that none of the studies discussed during this time frame specifically targeted an ethnic or indigenous population. Gagliano's review identified several video programmes that increased short term viewer knowledge, two of which focused on diabetes education. Ward et al. (1984) found increased understanding of insulin therapy among a cross section of diabetics exposed to an educational video. Lawson et al. (1976) explored the use of video for low literacy audiences and reported that after viewing a video, renal patients with low literacy skills had post test scores equal to patients with high literacy skills. Gagliano's review also cited studies designed to test a key premise of social learning theory, that observing role models (video modelling) increases the likelihood of others adopting the positive behaviour. Of the six studies targeting adults, all had positive results. It should be noted that all of the studies involved stressful situations (for example dental practices) that make their generalisability limited for my review. Gagliano (1988) concluded that when applied to well defined stressful situations, video modelling can decrease anxiety, and increase knowledge and coping ability.

The only other comprehensive review of the effectiveness of video in modifying health behaviours was published in 2012 (see discussion below). Kreuter and McClure (2004) argued there are so few studies evaluating the effectiveness of individual channels of communication because it is so difficult to isolate effects. Researchers must also take into account the content of

the message, who the messenger is, and the makeup of the audience receiving the message. Multiple communication factors as well as the specific strength of each medium make it difficult to isolate specific effects (Kreuter & McClure, 2004). They do cite a 1993 meta-analysis that found that video was second, behind face-to-face communication, for the largest source effects that can be attributed to message media (Wilson & Sherrell, 1993). Kreuter and McClure's review of the existing literature led them to conclude that video is most effective when it features credible and likeable people delivering the message.

Tuong, Larsen and Armstrong (2012) searched major databases to identify random control trials published between 1975 and 2012 evaluating the effectiveness of video interventions to modify health behaviours. Twenty eight studies covering a wide range of health behaviours were included in their final analysis. Two of the studies are of particular interest as they used video education to affect the lifestyle and behaviour of patients with type 2 diabetes. In a 2009 study, Glasgow et al. (2009) evaluated the effectiveness of a diabetes self-management DVD compared to classroom-based instruction. One hundred and eighty-nine adults with type 2 diabetes participated. The researchers reported that at the six-month follow-up, the DVD produced results that were not significantly different than classroom-based instruction. In a 2010 study conducted by Dyson, Beatty and Matthews, 42 newly diagnosed type 2 diabetic patients were recruited and randomly allocated to either a video education or control group. Data were collected at baseline and six months after the intervention. At six months, the intervention group showed increased knowledge compared to the control group. The intervention group showed slight improvements in cholesterol and increased physical activity. There were no significant changes in the control group. The researchers concluded that the brief video intervention increased diabetes knowledge amongst those newly diagnosed with type 2 diabetes and as a result may be an effective form of education (Dyson et al., 2010).

Overall nine of the twenty eight studies identified by Tuong et al. (2012) reported significant changes in the targeted behaviour. The majority of studies reported non-significant changes in comparison to a control group in at least one of the behavioural changes evaluated. The authors offer several explanations to account for the differences in reported evaluated outcomes. Each study had different control groups and the authors argue that control groups that also had educational value such as telephone counselling would naturally account for a smaller effect size in comparison with a video intervention. Likewise, as suggested by Kreuter and McClure (2004), the content of the message can impact effectiveness. Tuong et al. (2012) suggest message

framing theory might have had an impact on results, with gain-framed messages being more effective than loss-framing messages in encouraging behavioural change.

Like Gagliano (1988), the authors found that video modelling can influence behavioural change. They cited studies that found that active and visual demonstrations of the desired behaviour on video facilitates viewer learning (McDaniel & Rhodes, 1998; Mynaugh, 1991; Wood, 1996). And importantly for my study they note that video modelling can be further strengthened when those demonstrating the behaviour reflect the cultural, racial and ethnic backgrounds of the target audience (Steinke, 2001). As discussed earlier in the introductory chapter, a major gap in the literature is that few health communication interventions identify the use of theory used in the design of the intervention. Similarly Tuong et al. (2012) found that only eight of the twenty eight articles evaluated reported what theory was used.

### **13.2 Video health communication with Māori**

Digital communication has the potential to be a culturally sensitive form of communication. Bishop (1996) wrote that story is still a culturally preferred medium of instruction for Māori. “Historically, Māori as an oral culture devised methods to pass on the multiplicity of knowledge that any culture gathers and constructs about itself. Story was one of the common ways of imparting knowledge” (Bishop, 1996, p. 25).

A comprehensive review has identified only one Māori diabetes awareness video with an evaluation component or published research. The video, *Let's Stop Diabetes Now*, was produced in 1995 and the focus was on primary prevention among Māori, Pacific Island and European communities. Up until that time, diabetes videos produced in New Zealand were only focused on diabetes management (Fleming, Simmons, Leakehe, & Voyle, 1995). It appears that the production of the video did not closely follow principles of effective health promotion design for ethnic or racial groups. Notably, the video content for the Māori version was modified from the basic European based content rather than original content designed specifically for a Māori audience. The Ministry of Health considers culturally appropriate resources to be those that are specifically created for Māori rather than adapted from existing resources intended for non-Māori audiences (Ministry of Health, 1994). Three versions of the video were created with specially adapted segments for Māori and Pacific audiences. An ethnically diverse group participated in the shared content sections while Māori featured in the adapted sectors targeted specifically at a Māori audience. Scripts were written by health professionals with input from Māori cultural advisers and a dietician.

Attempts to locate the video have been unsuccessful. This is probably due to the age of the film and the rapid change in communication technology since the film was originally released on VHS. However, from the description provided by Fleming et al., the film's content appears to be a good example of what Kreuter et al. (2003) describes as *peripheral strategy* and Resnicow et al. (1999) defines as *surface structure*. While the film featured Māori people and easily recognisable imagery, it did not employ any health communication theory, nor did it incorporate formative research or pre-testing with the target audience. The Māori version of the video was shown to Māori audiences at four different locations and open-ended questions were asked in order to evaluate the video's cultural relevance and effectiveness. The results demonstrated clear differences in responses between the recruitment locations. For example, the Māori version was rated as very/completely culturally appropriate by 76% at one site, but by only 43% at another (Fleming, Simmons, Leakehe and Voyle, 1995). As the authors cautioned, there is not homogeneity of views within ethnic groups in regards to what is considered culturally appropriate. They found that groups who were more immersed in Māori culture were less likely than other viewers to perceive the video as culturally appropriate. The authors noted that while a lot of the content was similar, important ethnic differences were evident in both perception of content and in how that content was effectively presented. They concluded that different ethnic groups perceive audio-visual material differently and that these differences need to be acknowledged and addressed when creating diabetes materials (Fleming et al., 1995).

In 2002, as part of a separate study, another focus group discussion about *Let's Stop Diabetes Now*, was completed (Win, 2002). As part of a needs assessment for a new diabetes prevention video she wanted to create, Christchurch nutritionist Cecileah Win led a focus group discussion about diabetes video resources. Health professionals in the group she interviewed commented that both the visual imagery and the health messages of *Let's Beat Diabetes Now* were too negative. Others commented that the health messages were unachievable and unrealistic. Several participants criticised one of the Māori men featured in the video as being stereotypically Māori and using "jungle bunny" speech. The role playing and acting were disliked with group members instead expressing a preference for the use of real people. Cecileah Win, the researcher, also noted the video's emphasis on individual people and the absence of story, Māori language, music and Kaumatua (elders) (Win, 2002). This is in contrast to advice that the most effective videos for Māori are based within a cultural belief system of tikanga Māori (custom). They should be story and whānau (family) focused and utilise role models and Kaumatua to strengthen the messages (Ministry of Health, 1994). Win supported her critique with additional research that

argued the effectiveness of food and nutrition messages for Māori depends on “who is delivering the message, how the message is presented, and what the message is (Pihama, 1989).

As part of her literature review, Win also discussed a Ministry of Health produced film, titled *Keeping Well with Diabetes: Akey and Simon’s Story*, released in 2000, which did include Māori language, music and a whānau approach. My attempts to locate the film have been unsuccessful and it has been impossible to ascertain the process by which the film was created. Unlike *Let’s Stop Diabetes Now*, there has been no published evaluation or discussion.

Win concluded that there was a need for a Christchurch focused nutrition-related diabetes prevention video for Māori because the existing resources were dated, were not modelled on effective health communication principles with Māori, were not focused on South Island Māori and therefore did not reflect the tikanga (culture) of the South Island, and from a practical perspective, did not discuss eating healthily on a limited budget. As a registered dietician Win recommended the creation of a nutrition focused diabetes prevention video based in a Māori cultural belief system with whānau at the centre and with a focus on positive messages (Win, 2002). Some of the significant recommendations she made were that more research be conducted on diet and key behaviours, focus groups held with the target audience, appropriate behavioural change theories be utilised, and that the resource be pre-tested with formative and process evaluation conducted. Win then collaborated with a production company to produce a new nutrition focused video resource. (*E Kai, E Kori, E Ora*). Because no follow up research was written or published it cannot be ascertained if any of Win’s recommendations were actually implemented in the creation of the video. I have attempted to contact Win’s academic supervisor but follow up emails requesting additional information have not been responded to.

In addition, it is important to note that Win’s study has some understandable but significant limitations. First, the study was part of a student practicum project for a postgraduate diploma and Win’s time spent on the project development would have been limited. Second, she approached the study as a nutritionist with no expertise in health communication or focus group research. Third, in her write up, Winn discussed a number of weaknesses in her research design. These included

- Low recruitment numbers for the community member focus groups. Only three people attended the first session and one session had to be cancelled due to insufficient numbers



- A sample not reflective of the population as a whole (four of the six participants in the community member focus groups worked in health care and fifteen out of nineteen of the total number of focus group participants were female)
- An inexperienced facilitator
- Too many questions posed in allocated discussion time leading to time management issues, questions not asked, and potentially valuable information being skipped over
- Partial transcription
- Failed recording during one discussion

From this review of existing video resources it is clear that there is an identifiable need for a culturally appropriate digital diabetes resource, modelled on effective health communication principles, employing behavioural theory, and reflecting the tikanga of the South Island. In the following section I will explain why my study will employ a Community Based Participatory Research approach to develop this resource.

#### **14. Community Based Participatory Research (CBPR) interventions for prevention or delay of type 2 diabetes**

For many minority populations with the highest risk for diabetes and its complications, many health education programmes designed for the general population may not adequately address their cultural perspectives on health issues. Culturally competent interventions are needed to effectively reach these minority populations (Gilliland et al., 1998, p. 167).

CBPR studies that target cultural as well as community life are particularly suited to interventions with well-defined high risk populations. Empirical research data demonstrates that diabetes can be prevented or delayed with lifestyle changes and having the community involved in the design and implementation of diabetes interventions may be critical to success (Engelgau et al., 1998). Because lifestyle is tied to community, culture and values, successful CBPR programmes incorporate social and cultural components (Harris & Zinman, 2000). In addition to promoting lifestyle changes, community based approaches can assist researchers in identifying social factors like community and family support that can influence health behaviours. They are valued by local communities who can contribute to ensuring the cultural relevance of the interventions (Satterfield et al., 2003).

Satterfield et al. (2003) conducted a literature review of community based interventions for the prevention or delay of type 2 diabetes published between 1990 and 2001. They identified sixteen peer-reviewed studies, with most of them targeting high risk minority populations. Of the nine studies targeting adults, most reported small but positive changes in knowledge or the adoption of physical activity. Limitations reported included a lack of control groups, low response rates, lack of rigorous evaluation design and short intervention periods. The authors concluded that research on community based prevention of diabetes was still in its early stages and they argued that there is an ongoing and critical need to conduct and publish research and share details on the process, results and lessons learned (Satterfield et al., 2003).

#### **14.1 Community based projects: New Zealand**

Two of the studies cited in Satterfield's literature review were pilot studies conducted in New Zealand. The first, part of a multifaceted programme was a diabetes awareness and exercise programme in a multi-ethnic workforce (Simmons, Fleming, Cameron, & Leakehe, 1996) and included the production and use of the video, *Let's Stop Diabetes Now*, critiqued above (Fleming et al., 1995). The second pilot, part of the same large programme, included Pacific Island churches in the delivery of a programme to reduce risk factors for diabetes among Western Samoans (Simmons et al., 1998). Both studies took a community based approach to programme development which the authors defined using Labonte's definition of community development: "the process of organizing and/or supporting community groups in identifying their health issues, planning and acting upon their strategies for social action/change, and gaining increased self-reliance and decision making power as a result of their activities" (Labonte, 1993).

The researchers' rationale for using this approach was that it is particularly suited to initiatives with both indigenous and minority ethnic groups as it incorporates innovation, and reaffirms values in ways that empower participants (Simmons et al., 1997). As important, they noted that diabetes prevention focuses on changing patterns that are resistant to change because they are deeply rooted in culture and social relationships (Green & Kreuter, 1999). However, while a community approach was employed and clearly valued, neither of the published articles on the pilot programmes described the process for engaging the community in the development of the programmes. The multi-ethnic workforce programme employed a quasi-experimental approach to evaluate the acceptability and impact of the programme (Simmons et al., 1997). The intervention group received a community diabetes educator presentation, a video presentation and a four month exercise programme. The other group served as a control. Using a questionnaire and anthropometric measurements, the researchers found that six months after the

intervention ended the intervention group had increased diabetes knowledge in comparison to the control group. They also reported an increase in regular exercise while the control group had decreased exercise by nine percent over the same period. Simmons et al. (1998) concluded that diabetes knowledge and exercise can be increased with a combination of culturally tailored exercise techniques and community educator/video presentations. Although I addressed the shortcomings of the video in my earlier critique it is impossible to assess the video's overall effectiveness as it was one component of three in this programme. However I would suggest that results might have been improved with closer attention to the design and creation of the media content.

Similarly an assessment of the church based programme using a community development model found differences between the intervention church and control church. These included stable weight (intervention group), increased weight (control group), and an increase in diabetes knowledge and exercise in the intervention church (Simmons et al., 1996). A follow up study of a second assessment published in 2004 led the researchers to conclude that community based lifestyle programmes can reduce diabetes risk but that increasing diabetes knowledge is not necessarily associated with healthier lifestyle choices (Simmons, Voyle, Fou, Feo, & Leakehe, 2004).

## **14.2 Community based projects with indigenous communities: International examples**

Internationally, CBPR studies with indigenous populations show some promise in addressing type 2 diabetes prevention. Two long term initiatives in Canada, The Kahnawake Schools Diabetes Prevention Project (KSDPP) and The Sandy Lake Health and Diabetes Project (SLHP) have documented long term benefits of participatory research and serve as models for the design of interventions and evaluations of diabetes prevention projects with indigenous populations.

### **14.2.1 The Kahnawake Schools Diabetes Prevention Project**

The KSDPP began in 1994 and was a community based participatory research project conducted with a Mohawk community. The long term goal was primary prevention of type 2 diabetes, by promoting healthy eating and increased physical activity among six to twelve year old children. The researchers argued that because of the Native Americans holistic approach to health, the participatory model was most fitting. Populations based programmes are more supportive of the culture, traditions and value systems of Native Americans (Macaulay et al., 1997). In contrast, the high risk approach attempts to screen and treat high risk individuals and typically involves a

medical model and randomised studies. As Macaulay (1994) explained in her discussion of the ethics of research, Native American communities value participatory research because it requires partnership and collaboration which ensures cultural relevance, creates local knowledge and allows for participation in decisions for actions based on research results.

The participatory approach employed in the Kahnawake project incorporated native Mohawk traditions and local expertise with the objective of mobilising the community and fostering community empowerment and ownership (Macaulay et al., 1997). A community advisory board (CAB) was created to ensure broad involvement and the empowerment of the community over decision making. The CAB advised on intervention and evaluation objectives, activities, culture and traditions. Board members recruited from the community ensured cultural relevance, promoted the goals of the project to their own networks and became role models for healthier lifestyles. In order to create community awareness and mobilisation, the research team made extensive use of local media. This included advertisements in local newspapers, public service announcements on the radio and frequent use of posters. By incorporating a variety of communication channels the researchers could expedite the diffusion of health promotion messages. Results indicated a high level of community participation and the adoption of healthy behaviours in the school (Macaulay et al., 1997). The study's authors attributed this to full and active community participation. "Their collective wisdom adds a perspective that broadens interpretations, increases the project's effectiveness, helps to decrease harm and improves the credibility of oral and written results, which saves the community from potential stigmatisation" (Macaulay et al., 1999, p. 776). This study was later used as the basis for the development of explicit principles and guidelines for community based interventions (Potvin, Cargo, McComber, Delormier, & Macaulay, 2003).

#### **14.2.2 The Sandy Lake Health and Diabetes Project (SLHDP)**

The Sandy Lake Health and Diabetes Project (SLHDP) was initiated in 1991 and has run for over twenty years. The partnership between Sandy Lake First Nation and academic researchers is a model of culturally appropriate participatory research and has resulted in numerous community wide interventions including a local diabetes radio show and a schools based diabetes curriculum (Kakekagumick et al., 2013). Community members and researchers shared the decision making on all aspects of planning, implementation and evaluation. Research results were also shared and discussed with the community prior to publication. The project had several objectives including the use of formative research and ethnographic data collection techniques to develop culturally appropriate intervention strategies to modify risk factors for diabetes and its complications. The

community intervention programme focused on prevention education and utilised media including a weekly radio show and presentations on local cable television (Macaulay et al., 2003). In reflecting on the successes and longevity of the programme the researchers have emphasised that the community's endorsement was crucial in legitimising the project and enhancing the relevance of the research. For example, the schools based diabetes curriculum was developed by a PhD student and local Oji-Cree teacher with guidance and input from community elders (Saksvig et al., 2005). Two evaluations of the school programme consisting of a student questionnaire, dietary recall, anthropometric data and physical activity testing found improvements in self-efficacy and knowledge of health and nutrition (Kakekagumick et al., 2013).

In a 2003 paper describing KSDPP and SLHP the authors discussed several important commonalities. The community based model employed emphasised shared decision making, “research *with* communities, not research *on* or *about* communities.” (Macaulay et al., 2003, p. 467). They noted that by including community members in key positions this developed trust, ensured local values were incorporated and fostered a sense of community ownership.

### **14.2.3 The Haida Gwaii Diabetes project**

Another example of CBPR with an indigenous community is the Haida Gwaii Diabetes project conducted in two First Nations villages in British Columbia, Canada. The objectives were to develop a better understanding of Haida beliefs about diabetes in order to develop culturally sensitive approaches to prevention and management. Herbert (1996) described the process employed and how the project used community based research as a tool for empowering both Aboriginal community members and members of the research team. A participatory research paradigm, along with well-defined principles by which the research team agreed to operate, addressed the concerns that the Aboriginal community had about the risks of research. Researchers utilised Wallerstein's definition of empowerment as “a social action process that promotes participation of people, organizations and communities towards the goals of increased individual and community control, political efficacy, improved quality of community life and social justice” (Wallerstein, 1992 as cited in Herbert). Accordingly, the project was designed to increase the community's sense of self-efficacy by building on local strengths and knowledge systems. Working principles were established that included joint analysis and interpretation of research in order to ensure accuracy and avoid misunderstanding. The project team also regularly updated and consulted with the community in discussions with key informants, and at traditional Haida feasts. Discussed examples of empowerment resulting from this process included the

community health representatives use of focus groups as a tool to determine how to use the funds made available to the community and statements of support by community leaders (Herbert, 1996).

#### **14.2.4 James Bay Cree Diabetes Project**

Boston et al. (1997) explained how they adopted a participatory research approach with Aboriginal Canadians in order to study what meaning the Cree Indians gave to the increase in diabetes among their people. This methodological orientation was predicated on the premise that the views and experiences of the James Bay Cree had to be built into the process from its very inception. By giving voice to the Cree experience, interventions could be shaped by the community's experience of the disease. In their description of the project's background the researchers noted that few studies have concentrated on the perception and lay understanding of diabetes within Aboriginal communities. The researchers employed a qualitative approach with data collection consisting of interviews, participant observation, field notes and documentary evidence. Cree community health workers were trained in qualitative techniques and led one-on-one interviews with Cree with diabetes. The interviews were then jointly analysed at workshops consisting of the Cree workers and the academic research team. The academic researchers discussed how the participatory approach required a redefinition of the relationship between the researcher and the researched. It required professional researchers to equally value lay knowledge skills and experiences (Boston et al., 1997). In doing so, the researchers identified strong social and cultural barriers and communication issues that could be used to inform practical programmes and health policy.

#### **14.2.5 Diabetes prevention with a rural Aboriginal population in British Columbia**

In contrast, a participatory approach employed for another diabetes prevention programme in the rural Aboriginal population of British Columbia, Canada reported few changes in quantifiable outcomes. Daniel et al. (1999) outlined the study design and suggested weaknesses of the study that potentially affected outcome. Like previous studies discussed above, the researchers documented failures in Aboriginal diabetes education due to a lack of sociocultural relevance, unrealistic expectations for behaviour change and discrimination within the healthcare system. They argued for community based action hypothesising that initiatives will be more effective if community members are actively involved in the planning and intervention process. The project design was quasi-experimental with an intervention community and two comparison communities. Interviews and qualitative analysis were used to explore local perceptions of

diabetes in order to shape the strategies for the intervention. In describing the theoretical model the researchers stated goal was to integrate Aboriginal logic and belief systems with epidemiological knowledge of the determinants of diabetes and theories of behavioural and environmental change. Bandura's social learning theory was the foundation for the intervention. The paper described the target areas identified during data analysis and listed the activities developed for the programme, including a media campaign. Educational articles were published in newsletters and stories were carried in newspapers, television and radio. Cohorts were tracked over a sixteen month intervention phase and measured at baseline, midpoint and completion. The researchers reported that improvements were seen in health and awareness. For example, there was greater participation on local sports teams and increased requests for information and discussion of diabetes at public gatherings.

Nonetheless, Daniel et al. (1999) concluded that the results did not demonstrate any quantifiable evidence of effectiveness in terms of measurable change related to diabetes prevention or control. The research team discussed some possible reasons. The main argument was that there was not enough time to develop and implement the intervention and they suggested that more time for diffusion with interventions tailored to stages of change might be more effective. They also argued that the developed interventions still related more to the health professions culture than to Aboriginal culture. Consequently interventions did not clearly unite theory or previous research with the results gathered from the qualitative analysis.

Some important lessons can be garnered from this review of CBPR projects. Successful research projects are built on genuine partnerships. Likewise, participation in decision making ensures cultural relevance. Qualitative research methods can move beyond statistical analysis of a community and provide broader understanding of indigenous experiences. Furthermore, co-analysis strengthens results by broadening interpretations and helping to avoid misunderstanding. This requires that academics equally respect and value the wisdom of their community partners. The final section below builds on this analysis and the argument for utilising video by describing the literature on participatory research approaches in the creation of stand-alone health promotion videos.

### **14.3 CBPR studies and digital video**

Several of the examples discussed above were multiple interventions with the media component predominantly used to create community awareness and expedite the diffusion of health promotion messages. Other studies have specifically employed participatory research approaches

in the creation of stand-alone health promotion videos. In an article outlining the process for creating videos using CBPR principles, Chavez et al. note several strengths

...it can be a means of engaging community members, building partnerships, and strengthening community ownership, while also disseminating health promotion information in ways that appeal to a broad community audience. Thus, participatory video making acts as a bridge between multiple communities, invigorating partnerships and implementing creative collaborations. (Chávez et al., 2004, p. 395)

Furthermore, they suggest that video can be an effective health promotion tool because it allows for innovative ways to document and represent people, places and issues while accommodating power differences between researchers, institutions and community. It can give voice to and empower participants who are not typically engaged in research by creating the opportunity to be heard (Chávez et al., 2004).

As already argued, digital video has the potential to be a culturally sensitive form of health communication with Māori because story is still a culturally preferred medium of instruction (Bishop, 1996). Storytelling and narrative has been shown to be an effective way to engage non-English speaking minority ethnic groups in diabetes education (Greenhalgh, Collard, & Begum, 2005). Like Chávez, O'Mara suggests the participatory process is an effective approach for creating health videos with diverse ethnic and cultural communities (O'Mara, 2012). He argues its strength is that it can bring together health workers, community members and stakeholders "in a coordinated approach to community health education that is a reflective, critical and transformative experience for participants" (O'Mara, 2012. p. 2). O'Mara references several researchers who have discussed successful and effective participatory video production. Gubrium (2009) found that digital storytelling is an innovative CBPR method that can increase a community's ability to address local health issues. Not only is it a way for communities to prioritise their own health issues, it is also a way to empower participants to tell their own stories: "Digital stories can influence indigenous healthiness and resilience by offering a means of owning and being able to tell one's own story" (Gubrium, 2009, p. 197). Gubrium has evolved the model to include workshops where participants are trained in creating their own video stories.



Hunter et al. (2009) discovered that an innovative approach including multimedia, interactive kiosks, and documentary storytelling initiatives effectively engaged indigenous Queenslanders in a variety of health promotion interventions aimed at reducing indigenous health inequalities. The National HITnet Development programme used narrative and documentary approaches in the development of modules for alcohol, sexual health and bush food. The researchers reported that working directly with the affected communities in the development and production of resources helped privilege local and traditional knowledge and influence personal and group agency. They found that narrative and performance is particularly important in indigenous populations where it is customary to receive information by listening and watching rather than reading (Hunter et al., 2009). The researchers reported that preliminary findings from a survey of fifteen service providers and semi-structured interviews with six film participants indicated a clear preference for narrative rather than didactic material. However, details of the survey design were not outlined and the reporting of survey data makes it impossible to validate the statement or ascertain whether there was a change in baseline knowledge or behaviour. But excerpts from the semi-structured interviews support the argument that involving the community increases personal and group agency.

Chiu (2009) described a participatory action research project whereby four ethnic groups of women were actively engaged in producing a breast screening video. She wrote that the critical engagement of communities in health promotion is important not just because it can result in culturally appropriate narratives but also that the creative process itself can empower communities. Chiu believes that by engaging women in all aspects of video production, and developing their skills, it is akin to the conscientisation process described by Paulo Friere (1970). The created narratives act as a challenge to the deficit model typical of conventional health videos which positions ethnic and racial minorities as responsible for their poor health.

O'Mara (2012) concluded by identifying five major themes that emerge from the literature on effective participatory processes for developing digital health videos with minority communities. Each stage of film production should

- 1) Bring together and empower community members, health workers and artists
- 2) Employ narrative and storytelling techniques to more effectively engage with communities
- 3) Employ a communication style that reflects the preferences of the participants. Continuously evaluate throughout the production
- 4) Recognise how social context can effect health

- 5) Create a critical and transformative space for participants (O'Mara, 2012, p. 7)

## **15. Conclusion**

This chapter outlined, through reference to the pertinent literature, an argument for utilising a community based participatory research approach in order to create an effective digital media resource for Māori at risk for type 2 diabetes.

A review of social marketing campaigns targeting Māori highlighted that the foundation for successful behaviour change messaging is a culturally appropriate theoretical framework and a clearly identified health behaviour theory. Both the social marketing and CBPR literature indicate that in-depth qualitative interviewing and culturally appropriate processes are important for identifying relevant behavioural determinants. There is further evidence that effective health communication requires culturally tailored messaging, role models and credible likable people delivering the messages.

It was noted that there have only been a few video/digital resources about diabetes produced for Māori even though Ministry of Health reports support their use as an effective educational tool. There is some evidence in the international literature that culturally sensitive videos have been effective at influencing behaviour change and that digital storytelling is suitable for health communication with indigenous populations. Nonetheless, the videos produced in New Zealand to date were shown to be of limited value due to lack of culturally tailored content based within a cultural belief system of tikanga Māori (custom) and a failure to employ behavioural theory.

The importance of a community based approach to health communication was underlined by both the health promotion literature and the reported literature on community based projects previously conducted in New Zealand. As the researchers involved with Ngati and Healthy concluded, community involvement ensures both relevance and acceptance. However, gaps in the literature remain. In their 2003 review literature review of community based interventions for the prevention or delay of type 2 diabetes, Satterfield et al. (2003) concluded that research was still in its early stages and they argued that there is an ongoing and critical need to conduct and publish research and share details on process, results and lessons learned. Several examples of CBPR interventions with Native Americans were discussed that outlined how to establish effective participatory research for type 2 diabetes health promotion. In addition, there is some evidence that the participatory process is an effective approach for creating health videos with diverse ethnic and cultural communities.

The process of working with a community needs to be made transparent and be documented. There is a gap in the literature when it comes to understanding the process of developing relationships and consulting with the Maori community. While Ngati and Healthy's participatory community development model and Simmons et al.'s community development model appear to share similarities with CBPR, none of the published research documents the process employed in consulting with the community. Given that partnership development and collaboration is central to participatory research models there is a need for research that makes explicit the process of engaging community members.

I have also described how successful health communication interventions should make explicit what behavioural and communication theory and principles were applied in shaping the health communication intervention. One of the most critical conditions for a successful communication intervention is an understanding of the determinants of behaviour in order to influence the behaviour (Randolph & Viswanath, 2004). Therefore, it is notable that none of the existing diabetes resources (print or digital) produced in New Zealand have made explicit the use of theory to inform and shape the communication messages. My study will address this gap and document and discuss what theories are used in the creation of the digital resource.

Furthermore, effective communication interventions are needed to address the disconnection between medical professionals' biomedical perspective on the disease and the cultural and experience based beliefs that influence how Māori experience and understand diabetes. As Boston et al. (1997) noted, few studies have focused on the perception and lay understanding of diabetes in indigenous populations or the social and cultural meanings of the disease. Notably both the community based New Zealand based diabetes initiatives discussed in this review relied on survey data and epidemiological data. Therefore this study is designed to address this gap and the failure to communicate health information that reflects Māori cultural practices in ways that are appropriate for use in Māori communities. The created digital resource will depend on culturally relevant design that pays close attention to environmental barriers and community norms, behaviours, values and beliefs.

Finally, in both the introductory chapter and this literature review I have shown that a tenet of effective health communication design is that planners need to frame messages in culturally appropriate ways which means targeting and tailoring media programmes (Kennedy & Abbatangelo, 2004; Resnicow et al., 2002). One of the weaknesses of the Lets Beat Diabetes print campaign and the *Let's Stop Diabetes Now* video was that they were too inclusive. LBD targeted a general population and *Let's Stop Diabetes Now* was modified from the basic

European based content rather than being original content designed specifically for a Māori audience. As a result neither resource was specifically tailored to the target group's experiences, values and needs.

A CBPR approach to documentary creation will be employed in this study to engage community members, build partnerships, and strengthen community ownership, while also disseminating health promotion information in ways that are both theoretically sound and culturally appropriate. In the following chapter I will build on the arguments presented in the literature review to describe a CBPR research model that build on the CBPR literature, links to indigenous principles and allows for a qualitative research design that increases the chances of creating a culturally relevant digital resource.

## **Chapter III. Methodology**

### **Overview**

In the last chapter I made the argument for utilising a community based participatory research approach in order to create an effective digital media resource for Christchurch Māori at risk for type 2 diabetes. In the first part of this chapter I will describe CBPR in more detail. I will explain widely recognised principles before turning to how scholars have defined CBPR. This discussion will include historical background and epistemological traditions. Following this I will outline why I believe CBPR is an appropriate research approach with Māori. This will include a discussion of both the significant similarities and differences between CBPR and Kaupapa Māori and the implications for the researcher and research design. Particular attention will be paid to eight indigenist principles that guided the research process and final evaluation. I will finish this part of the discussion by acknowledging some of the questions about and criticisms of CBPR. In the second half of the chapter I will outline my research design and methods. My research design is a multi-method qualitative approach. The approach to partnership development, key informant interview and hui will be described and arguments presented as to why these are appropriate methods. I will conclude with an explanation of the evaluation criteria that guided the assessment of the completed research.

### **16. Community Based Participatory Research (CBPR)**

Community Based Participatory Research provides a model for enacting local action oriented approaches (Denzin & Lincoln, 1994). It “focuses on social, structural, and physical environmental inequities through the active involvement of community members, organizational representatives, and researchers in all aspects of the research process” (Israel, Schulz, Parker, & Becker, 1998, p. 173). Since the early 1990s, CBPR has been viewed as a credible and legitimate research approach in public and behavioural health (Chávez, Duran, Baker, Avila, & Wallerstein, 2008; Mendenhall et al., 2010) “because of its ability to inform understanding of patients’ experiences, improve or generate services, facilitate community outreach and engagement, enhance education, and augment cultural awareness” (Mendenhall et.al, 2010, p. 362). One of the fundamental characteristics of community-based research in public health is an emphasis on the participation and influence of non-academic researchers in the process of creating knowledge (Israel et al., 1998, p. 177). The research approach is rooted in a commitment to share power with and engage community partners in the research process. This means that partners should be

involved in all stages of the research (Israel, Eng, Schultz, & Parker, 2005a; Israel et al., 1998; Mason, 1996; Minkler & Corage Baden, 2003).

Kiefer et al. (2004) cite over a dozen studies that have demonstrated that community based research methods provide a reliable basis for planning successful public health interventions (Kieffer et al., 2004, p. 34). Such interventions are successful because they involve community participants in the planning and design stages (Israel, Checkoway, Schulz, & Zimmerman, 1994; Lewis et al., 1993; Marin et al., 1994). As important, the research approach aims not only to increase knowledge and understanding of a public health issue but to also use that knowledge to improve the health and well-being of community members either through direct intervention or policy change.

### **16.1 CBPR-Key principles**

In a comprehensive review of the literature, Israel et al. (2001) explained nine key principles of the CBPR approach. Acknowledging the wide range of applications, they noted that each principle's application is contingent upon the context, purpose and participants involved in the process.

- 1) Recognises community as a unit of identity
- 2) Builds on strengths and resources within the community
- 3) Facilitates collaborative partnerships in all phases of the research.
- 4) Integrates knowledge and action for the mutual benefit of all partners
- 5) Promotes a co-learning and empowering process that attends to social inequalities.
- 6) Community-based research involves a cyclical, iterative process
- 7) Addresses health from both positive and ecological perspectives
- 8) Disseminates findings to all partners
- 9) Involves a long term commitment by all partners (Israel, Schulz, Parker, & Becker, 2001)

Holkup et al. (2004) argue that what unites the variety of CBPR approaches is

- They all emanate from the same ontological paradigm
- They all rely on an epistemology of experiential and participative knowing
- All link action with research
- All recognise the importance of involving members of the study population in the research process (p163)

Viswanathan et al. identify two core ideas from the CBPR literature: (1) The reciprocal co-learner relationship between the researcher and the researched and; (2) the immediate and direct benefit of using new knowledge for taking collective action and effecting social change (Viswanathan et al., 2004, p. 25). They also identify four central themes.

#### CBPR

- 1) Recognizes the importance of social, political, cultural, and economic systems to health behaviours and outcomes ( An ecological approach)
- 2) Engages community members in choosing research topics, developing projects, collecting data, and interpreting results (collaboration)
- 3) Emphasises both qualitative and quantitative research methods
- 4) Puts high priority on translation of the findings of basic, intervention, and applied research into changes in practice and policy(action) (Viswanathan et al., 2004).

### 16.2 What exactly is Community Based Participatory Research?

According to one frequently cited definition, “CBPR is a partnership approach to research that equitably involves community members, practitioners, and academic researchers in all aspects of the process, enabling all partners to contribute their expertise and share responsibility and ownership” (Israel et al., 1998). The term CBPR has gained popularity since the 1990s. But as several CBPR scholars have noted there are, and continue to be, a wide range of terms used to define this partnership approach to research. (Israel et al., 1998; Israel et al., 2001; Viswanathan et al., 2004; Wallerstein & Duran, 2008). One reason for this is that participatory research is practiced in several academic disciplines and scholars use subject specific terminology to describe their participatory approaches (Israel et al., 1998; Wallerstein & Duran, 2008). For example, in education alone, Kemmis and McTaggart (2000) identify the use of ***classroom action research, critical action research and practitioner research***. Likewise, Israel et al., note the use of ***community based participatory, involved, collaborative and centred*** research in public health (Israel, Eng, Schultz, & Parker, 2005c; Israel et al., 1998). And since the late 1990s, the term *CBPR* has also been used in the health field to describe an orientation to research that involves the community in all aspect of problem identification, project planning, implementation, analysis and dissemination of research findings. (Israel et al., 2001; Wallerstein & Duran, 2008)

Other popular variations include:

- ***Participatory research*** (De Koning & Martin, 1996; Green, Daniel, & Novick, 2001; Hall, 1992; Kemmis & McTaggart, 2000; Park, 1992; Tandon, 1996)
- ***Action research*** (Fals-Borda, 1987; Hall, 1992; Reason & Bradbury, 2006; Stringer, 2007)
- ***Participatory action research*** (Whyte, 1991)

Minkler and Wallerstein (2008) note that an additional explanation for the wide range of terms is geographic location. ***Community based participatory research*** has gained popularity particularly within the United States, and ***participatory action research*** and ***participatory research*** in developing countries. ***Action research*** is more commonly used in Australia and New Zealand. The Ngati and Healthy diabetes project previously discussed was described by the researchers as employing a ***participatory community development model*** (Tipene-Leach et al., 2013) and Simmons & Voyle's study (2003) as employing a ***community development model***. Moreover, in recent years the terms ***action research*** and ***participatory (action) research*** have sometimes been used interchangeably as common principles have developed (Holkup et al., 2004; Wallerstein & Duran, 2008).

### 16.3 Putting the participatory into community based research

Israel, Eng, Schultz and Parker (2005a) argue that despite the long list of terms applied to participatory research, each one with a different emphasis, all the approaches are based on a commitment to carrying out research that both involves and shares power with community partners, leads to positive outcomes for community members, and results in social action. Accordingly it “focuses on social, structural, and physical environmental inequities through the active involvement of community members, organizational representatives, and researchers in all aspects of the research process” (Israel et al., 1998, p. 173).

There is a significant development in their argument between their 1998 review of the literature and a 2001 article where they outline the key principles. They first used the term *community based research* in their earlier work, then specifically used the term *community based participatory research* in 2001, to emphasise the importance of the equal participation of non-academic researchers in the process of creating knowledge and effecting social change. Israel et al. (2001) argue that there is a critical difference between the two terms. Community based research remains researcher focused and emphasises the community only as a physical location



for study and with limited community involvement. By contrast, community based participatory research privileges active community involvement and partnership with community members.

This position is reinforced by Green, Daniel and Novick (2001) who argue that CBPR is research conducted *with* a community as opposed to *on* a community. As Meredith Minkler (2004) comments, it is “community placed” rather than “community based” research. A similar point is made by Rifkin (1990) who states that participation is about active choice, engagement and the possibility of effecting change. It is not simply taking part. Holkup et al., (2004) agree that participatory research is distinct from action-oriented research primarily because of the central role that non-experts play. They suggest action research still emphasises the role of the expert whereas participatory research places the emphasis on community control and ownership of the problem. Similarly Minkler and Wallerstein (2003) distinguish CBPR as more than community outreach in that the goal is to incorporate community participation in order to facilitate change. My study design is guided by their definition of CBPR. It is a

...collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. [Community-based participatory research] begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities. (Minkler & Wallerstein, 2003, p. 4)

The emphasis upon collaboration and social change is reinforced by Viswanathan et al. (2004). A systematic review of over fifty conceptual arguments found that there is general agreement in the literature that CBPR is a collaborative approach to research with the goal of improving a community's health and creating an opportunity for the community to utilise the resulting research for social or political change and the overall betterment of the community. Likewise Green (1995) state that the purpose of producing new knowledge is to effect social change and McTaggart (1997) argues that the goal of participatory research approaches is social transformation.

## **17. CBPR: Historical and philosophical traditions**

Wallerstein and Duran (2008) describe how the theoretical and historical roots of the numerous participatory approaches to research are located in two separate traditions that occupy opposite ends of a theoretical and political continuum: The Northern tradition is a pragmatic “problem

solving utilitarian approach” exemplified by the action research of Kurt Lewin (1946). The Southern Tradition, is “openly emancipatory research which challenges the historical colonizing practices of research and political domination of knowledge by the elites,” and is exemplified by the work of Paulo Friere and Orlando Fals Borda (Wallerstein & Duran, 2008, p. 27).

The use of the term *action research* began with Kurt Lewin in the 1940s. Lewin challenged the positivist belief in objective knowledge and identified a gap between theory and practice. He believed practical problems could be solved and system improvements made, not by observational objective study, but by the active involvement in the research of those most affected (Minkler, 2004; Wallerstein & Duran, 2008). In his 1946 paper, “Action Research and Minority Problems,” he described the action research approach as “a spiral of steps, each of which is composed of a circle of planning, action and fact-finding about the result of the action” (Lewin, 1946, pp. 34-35). Minkler (2004) situates the Northern tradition in the theory of social action developed by Sociologist Talcott Parson, and a consensus model developed and practiced in the fields of education, organisational development and social psychology. The consensus model is predicated on a mutual exchange of ideas and a process of self-reflection between researchers and community members. This approach is based on the premise that social progress can be achieved by applying rational scientific knowledge and a process of continued self-reflection to real world problems.

The roots of the Southern tradition can be situated in the political and social changes of the 1960s. Most frequently referred to as *participatory research* or *participatory action research* this work is most closely associated with community development movements and critiques of the education system that emerged in the early 1970s in Latin America, Africa and Asia (Fals-Borda & Rahman, 1991; Freire, 1970, 1973; Hall, 1992; Hall, Gillette, & Tandon, 1982). As a result of their participation in these protests, some scholars began to question and challenge existing power relations, the role of researcher/researched and ownership of knowledge itself (Wallerstein & Duran, 2008). Influenced by Marxist critiques and liberation theology, these scholars rejected the positivist tradition of academia arguing it serviced and most benefited traditional power elites. Some educationalists and social scientists challenged what they perceived to be the colonising nature of research which they argued was of little benefit to communities and in fact subjugated the people academics “researched” (Brown & Tandon, 1983; Fals-Borda, 1987; Freire, 1982).

Particularly influential was the 1972 publication, *Pedagogy of the Oppressed*, a critique of colonial oppression, written by exiled Brazilian academic Paulo Friere. Friere challenged the

positivist tradition that dominated universities and educational systems by arguing that objectivity was a social construct and reality was always subjective (a matter of people's perception often based on their political power) rather than something that could be isolated as an objective truth. Friere advocated "Conscientization", a process through which poor or marginalised groups would first develop an awareness of the social and political forces influencing their lives and then use this awareness to guide their political actions (Kindon, Pain, & Kesby, 2008). Communities were no longer to be passive objects of study, but rather active and equal partners in the research process. At the same time, researchers' commitment to social justice required them to question their own role as knowledge producers in the research process and embrace the idea that knowledge was also produced by, and with input from, community members.

The critique of power inherent in CBPR practices makes this research approach a good fit for use with ethnic and minority populations that have been disengaged from power, experienced economic and political marginalisation, and felt exploited by research (Israel, Eng, Schultz, & Parker, 2005b; Minkler & Corage Baden, 2003). More recently feminist, poststructuralist, postcolonial and scholars of colour have continued to build on this research tradition. As Minkler argues, issues of gender, race, class and culture are integral to CBPR as they permeate every aspect of the research process (Minkler, 2004, p. 686).

As Minkler and Wallerstein (2008) acknowledge, situating the various terms used to describe the participatory research approach at a specific point on the continuum between the Northern and Southern traditions is difficult precisely because each individual research practice may be different according to the local context, historical precedents and political positions of the project stakeholders. But they argue to fully reflect the principles of CBPR in Public Health and achieve social justice, the gold standard for researchers should be to occupy the emancipatory end of the continuum (Minkler & Wallerstein, 2008, p. 11).

## **18. Epistemology and ontology: Knowledge traditions and power relations**

Positivist research design is based in a fundamental belief that objective knowledge and universal truths can be studied, revealed and documented. As Fletcher (2003) argues, one of the most fundamental beliefs that science generates about itself is that it produces objective knowledge. Accordingly, it has privileged "expert" academic knowledge most frequently located in university settings. The positivist paradigm conceives that there is an objective form of knowledge revealed through the collection of observable, quantifiable data by researchers

employing the correct methodology. Traditional scientific research approaches have placed primacy on maintaining a distant objective relationship with research participants to avoid invalidating research results (Guba & Lincoln, 1989; Kindon et al., 2008; Minkler & Corage Baden, 2003; Reason & Bradbury, 2006).

However, by the early 1970s, theorists and activists, both in and outside the academy, began to question the “fetish like idea of science as truth” (Reason & Bradbury, 2006, p. 29). A number of academic theories developed including critical theory, indigenous theory, postmodernism, poststructuralism and postcolonialism, all challenging the idea of objectivity. Drawing on the ideas of Habermas and Foucault, these researchers argued that far from being neutral and value free, science was a social construct that often supported existing power relations and maintained the status quo (Wallerstein & Duran, 2008).

The position that I take with my research is consistent with the CBPR tradition. Research, science and knowledge production are approached not as neutral or value free, but rather as an ideological process. Researchers adopting this approach “accept first and foremost that all inquiry is political by definition. Information does not exist in a vacuum but is generated within a specific articulation of power and is interpreted within the confines of established intellectual structures” (Fletcher, 2003, p. 32).

### **18.1 Valuing experiential knowledge**

I have previously argued that when designing effective health promotion messaging with Māori it is essential to use a culturally appropriate theoretical framework. As Linda Tuhiwai Smith (2000) explained, the Māori understanding of health does not follow the Western philosophical model which distinguishes between the mental and the physical. Later in the chapter I will further discuss Kaupapa Māori and the conceptualisation of Māori knowledge. Although there are important differences, both CBPR and Kaupapa Māori reject the idea of scientific objectivity and place value on multiple forms of knowledge, including knowledge situated outside of academia. Fletcher states that as a philosophy, CPBR is inclusive and incorporates multiple ways of seeing the world. Rather than locating and privileging academic or scientific knowledge, it acknowledges the existence of a plurality of knowledges in a variety of institutions and locations. In doing so, CBPR acknowledge the epistemological validity of local knowledge systems (Fletcher, 2003; Gaventa & Cornwall, 2008; Wallerstein, 2007). Likewise, Minkler (2004) argues that CBPR processes make explicit the deconstruction of power and the democratisation of knowledge and in doing so the experiential knowledge of community members is valued. This

represents a “counter hegemonic approach to knowledge production” (Kindon et al., 2008). Reason and Bradbury (2006) describe the action research tradition as “an extended epistemology” founded on diverse forms of knowing. And as Wallerstein and Duran suggest, CBPR raises fundamental questions of “by whom, about whom, and for what purpose this knowledge is defined? (Wallerstein & Duran, 2008, p.32). Inherent in this critique is the criticism that in discounting experiential knowledge, positivist research has silenced and obscured other voices. In critiquing the positivist tradition in public health, Buchanan (1998) maintains that positivism is actually an ideology that in valuing empiricism undermines opportunities to promote social justice. Kindon, Pain and Kesby (2008) argue that the participatory position is a radical one because it suggests “that it is not enough to understand the world but that one has to change it for the better.” (Kindon et al., 2008, p. 13).

Israel et al. (1998) reference the works of Guba and Lincoln (1994) and argue that CBPR is influenced by two paradigms, critical theory and constructivism. Critical theory encompasses poststructuralist, postcolonialist and feminist theory, and other forms of participatory inquiry that challenge the positivist paradigm. Critical theory is rooted in the perspective that reality is subjective. Accordingly, critical theorists believe that knowledge is a social construct and will always be mediated by a complex tapestry of socioeconomic, gender and cultural influences that simultaneously influence both researcher and participants requiring an active dialogue between the two. The constructivist position emphasises multiple realities that are all socially constructed. This paradigm emphasises the on-going and interwoven relationship between researcher and participants and suggests that research findings are directly influenced by, and inseparable from, this relationship.

## **18.2 Power**

Wallerstein and Duran (2008) state that in order to critique or address social inequalities and health disparities, it is first important to understand the bigger picture and ask who gets to exercise power? Knowledge is one form of power but it is created within a larger social system. I was reminded of this very early in the research design when in the exploratory stage, several people working within the health care system talked to me about first appreciating not only how resources are allocated but most important how health funding decisions are more widely discussed in New Zealand. One of the examples given was funding for mothers/women’s health. The observation was made to me that funding is readily allocated for fertility treatments for white middle class women in their thirties who are seen as sympathetic and deserving candidates but that neither the same level of funding or empathy were available for Māori or Pasifika

women who tend to have children much younger but have different needs associated with being young mothers.

These types of conversations were valuable because if the goal of CBPR is to produce knowledge that both challenges and changes the unequal distribution of resources based on race, class, gender etc., it is necessary to have an understanding of *how* power operates. To do so Wallerstein and Duran (2008) suggest looking at theories of political economy, and the work of Foucault. A political economy view is rooted in the assumption that resources are distributed on the basis of power rather than merit. For this reason, a political economy view of health care advises that the actions of key players can best be understood in relation to the power and class position held by each player (Minkler, Wallace, & McDonald, 1994).

Wallerstein and Duran (2008) discuss the work of Gaventa and Cornwall (2008) who ascertain that there are four distinct forms of power in CBPR. Those who espouse a pluralist liberal democratic view argue that there is an open market of ideas where power is accessible to all and that those who chose not to participate do so out of choice or indifference. A second view of power is the argument that certain ideas or issues are not openly accessible or freely discussed. Rather they are deliberately repressed by either social norms or individuals with a vested interest in maintaining the status quo. The third view of power holds that community ideas or individual challenges and grievances that challenge the status quo are deliberately repressed so that they are never openly discussed, let alone accommodated. Certain ideological interests are favoured and their ideas appear to be so normalised they are accepted without question. This conceptualisation of power informed my research because Pakeha society tends to emphasise individual lifestyle choices as central to good health (Hodgetts & Chamberlain, 2000). The New Zealand media has also been found to downplay racial explanations, emphasise personal responsibility and to ignore questions about levels of health care and services for Māori (Hodgetts, Masters, & Robertson, 2004). In contrast Mason Durie argues that understanding indigenous health requires recognition of historical, cultural and political forces that threaten health. These adverse forces include dislocation, poverty and cultural repression (Durie, 2001).

While Foucault identified these forms of power as repressive, he suggested a fourth way of conceiving of power and it is this view that ultimately guides my research thinking. Foucault argued power is based on relationships and is therefore contestable and open to challenge. Rather than seeing power as static, Foucault argued that at every level, (family, community, institutional) there are discussions and practices that both maintain, but also challenge, the dominant power structure and ways of thinking about and acting in the social world (Foucault,

1977, 1980). Wallerstein and Duran (2008) suggest that this way of looking at power holds great potential for CBPR practices. Hence while highly specialised academic research language can indeed be repressive and constrain how communities interact with researchers, CBPR that emphasises joint decision making and social action can lead to communities gaining research skills and challenging existing practices. In recognising that repressive power can restrain people's prospects for better education, living conditions and health, "emancipatory CBPR uncovers these mechanisms of control, biases, and internalized representations of reality, as a key strategy for change" (Wallerstein & Duran, 2008, p. 74).

### **18.3 Why CBPR is a good fit with Māori**

Because CBPR places primacy on power sharing and achieving social action and change, it is a good fit for work with minority communities who have felt shut out of the decision making process and reduces the gap between theory, research and practice (Israel et al., 2005; Horn, McCracken, Dino & Brayboy, 2008). As Minkler and Corrage Bandon argue, "incorporating community knowledge claims into scientific processes can radically shift not only the shape and direction of the research but, more fundamentally, the power dynamics of science production itself." (Minkler & Corage Baden, 2008, p. 254). It is an ecological approach that recognises a documented history of health inequalities based on race, ethnicity, class and gender and incorporates the active participation of the community in addressing these health problems (Green et al., 2001; Minkler & Corage Baden, 2003; Schulz, Israel, Selig, Bayer, & Griffin, 1998; Sullivan et al., 2001).

The ethos of CBPR is research *with* a community rather than *on* a community (Mohammed et al., 2012). In creating partnerships, and building on local knowledge and culture, CBPR processes allow for critical reflection on issues of power, privilege and racial discrimination and are considered to be an ethical, respectful and meaningful approach (Shalowitz et al., 2009). As Fletcher explains, CBPR is an important tool for researchers working with indigenous populations because it acknowledges different ways of knowing and gives equal weight to scientific and cultural expressions of knowledge (Fletcher, 2003).

As previously discussed there is a need for innovative approaches to diabetes education and prevention that reflect Māori cultural practices in ways that are appropriate for use in Māori communities. A tenet of effective health communication design is that planners need to frame messages in culturally appropriate ways which means targeting and tailoring media programmes (Kennedy & Abbatangelo, 2004; Resnicow et al., 2002). The CBPR approach is appropriate

because intervention strategies designed following its principles will reflect the cultural values, behavioural preferences, expectations and environmental context of the participating community (Kieffer et al., 2004). As Mason Durie advised

Behavioural change is dependent on many variables, including the socio-cultural factors that characterise a particular group. Targeting Māori behaviour patterns requires an understanding of both cultural and social factors so that the message is not received as an injunction imposed from above without any reference to local feelings or realities (Durie, 2001, p. 40).

Both researchers designing media campaigns and researchers designing public health programmes have called for increased sensitivity to diverse cultures and minority audiences when planning health education programmes (Marin et al., 1994; McLeroy et al., 1995; Resnicow et al., 2002; Vega, 1992). Health programmes for Māori must take into account the impact of colonisation on Māori health. As Voyle et al., (1999) outline, alienation and marginalisation have had disastrous consequences for Māori identity, cultural tradition, social cohesion, self-esteem and economic survival. Consequently morbidity and mortality data for Māori and other indigenous populations are far higher in comparison with non-indigenous populations (Voyle & Simmons, 1999, p. 1035). CBPR is rooted in an approach that acknowledges that inequities in health status are part of a complex social, political and economic system that includes factors such as poverty, racism, housing and employment (Israel et al., 2005, Israel et al., 1998).

## **19. Kaupapa Māori Research**

The Southern tradition of participatory research shares some similarities with Kaupapa Māori critiques of the Western research paradigm. Academics working in both areas challenge the historical colonising practices of research and the positivist paradigm. Māori scholar Linda Tuhiwai Smith notes that for indigenous people the history of research is “inextricably linked to European imperialism and colonialism” (L. Smith, 1999, p. 7). Research has historically privileged Western ways of knowing while at the same time marginalising indigenous knowledge systems. To Smith, “Research is a site of contestation not simply at the level of epistemology or methodology but also in its broadest sense as an organised scholarly activity that is deeply connected to power” (L. Smith, 2005, p. 48). She argues for a research approach



that is “transformative” in that its critique of power relations encourages institutional and social change and a central role for indigenous knowledge. Wallerstein and Duran (2006) argue that in order to be truly participatory and promote co-learning, researchers should acknowledge and incorporate indigenous practices, theories and research methodologies. Later in this chapter I will outline how my research design incorporated indigenist principles into the research process.

How closely Kaupapa Māori can be aligned with CBPR principles and practice is debatable. There are notable similarities in critiques of power and support for research leading to social action, but also significant differences in terms of epistemological traditions and methodological frameworks. Russell Bishop, a Māori academic in the education field, has written widely on Māori approaches to creating knowledge. Bishop’s critique of New Zealand’s research traditions has parallels with some CBPR academics discussed above whose work has similarly challenged the historical colonising practices of research and political domination of knowledge by academic and political elites. Bishop (1998) argued that a social pathology research approach has developed in Aotearoa (New Zealand) that has perpetuated colonial values and reinforced an ideology of cultural superiority where Māori are frequently depicted as unable to cope. Bishop states that this has prevented not only the development of power sharing processes, but also the recognition of diverse cultural epistemologies. He describes the emergence of Kaupapa Māori as a reaction to the neo-colonial dominance of research. It is a revitalisation of Māori culture, preferences and practices and a challenge to Pakeha/European research (Bishop, 1998, p. 200).

Graham Smith has described Kaupapa Māori as “the philosophy and practice of being and acting Māori,” which questions the right of Pakeha to exclude and dominate Māori and where “Māori language, culture, knowledge and values are accepted in their own right.” (G. Smith, 1992 as cited in Bishop, 1998). In a detailed literature review of Kaupapa Māori principles and practices, Tuhiwai Smith and Reid (2000) cite Bishop and Glynn (1999, p. 6.) who describe Kaupapa Māori as the “flourishing of a proactive Māori political discourse” and Sheila Walker (1996) who defines Kaupapa Māori as Māori initiated, defined and controlled. Tuhiwai Smith and Reid draw attention to the importance of Graham Smith’s 1997 dissertation, “The development of Kaupapa Māori theory and practice,” where they argue he deliberately co-opted the word theory in order to challenge a narrow Eurocentric interpretation of theory.

Kaupapa Māori educationalist Tuki Nepe (1991) emphasises Māori control and ownership and Te Reo (language) as central to Kaupapa Māori. It is distinct from Western approaches and centred on a Māori world view. To Nepe, Kaupapa Māori has distinct epistemological and metaphysical foundations and these foundations make it distinct from other academic

approaches. As Mahuika (2008) cautions, Kaupapa Māori is not a simple revamp of existing western theories using culturally appropriate Māori vocabulary. Rather Kaupapa Māori's epistemological foundations date back to the beginning of time and the creation of the universe. Similarly Linda Tuhiwai Smith (2000) states that this tradition

...frames the way we see the world, the way we organise ourselves in it, the questions we ask, and the solutions we seek. It is larger than the individuals in it and the specific 'moment' in which we are currently living. The significance of Kaupapa Māori to Māori language is tied to the connection between language, knowledge, and culture. (L. Smith, 2000, p. 230)

Tuhiwai Smith (2005) argues that thinking about research means considering not only epistemological issues but power issues. To transform research requires a distinctive set of Māori arguments, principles and frameworks that critique commonly accepted ways of conducting research and the way that knowledge has been constructed. Bishop and Glynn (1999) emphasise a central Māori epistemological concept of *Nga mahi a nga tpuna/taonga tuku iho* (the treasures handed down from the ancestors). They note that the Māori view of knowledge is very different from working in a traditional research model because information is not universally shared. Some knowledge only belongs to some people.

Rangimarie Mahuika (2008) notes that Kaupapa Māori has been described as a theory, but also as a method and methodology and this multifaceted use has complicated the discussion about epistemology. She believes it remains unclear where Kaupapa Māori sits in relation to other postcolonial theories because there are also various ways to interpret and apply Kaupapa Māori based on both the context and the content of the research. For example, in his critique of the theoretical underpinnings of Kaupapa Māori, Eketone (2008) positions Kaupapa Māori not just as philosophy but as a theory of social change aligned with critical theory. Eketone situates the work of Graham Smith, Russell Bishop and Linda Tuhiwai Smith within the critical theory tradition. Eketone references Graham Smith (1997, p. 38) who argued there are three key similarities between the two theories: *Conscientization*- a critique of the forces that disregard Māori knowledge, *Resistance*- proactively responding to oppression with social change and *Reflective Change*- applying what has been learned. To Eketone, Kaupapa Māori theory has been located in or alongside critical theory because the common factor in writings on Kaupapa Māori theory is a focus on resistance to oppression and western hegemony. Eketone is concerned that in

this positioning, Kaupapa Māori is too closely defined by its critique of power and resistance to western hegemony. He argues for a more constructivist approach to knowledge that values multiple ways of constructing reality and avoids defining itself in opposition to Western knowledge systems.

Mahuika (2008) also addresses the question of whether Kaupapa Māori can be described as anti-colonial. She points to the influence of notable non-Māori theorists such as Paulo Friere and Edward Said on the work of Russell Bishop, Graham Smith and Linda Tuhiwai Smith. Mahuika asks whether this represents an internal contradiction, “How can Kaupapa Māori be an anti-colonial theory based in specifically Māori ways of seeing and knowing the world, and yet draw on western theories and theorists for inspiration and support?” (Mahuika, 2008, p. 11). Mahuika asserts that it is unrealistic to believe that given over two centuries of colonial oppression a kaupapa Māori approach can be entirely free of western influence. She discusses the work of Graham Smith (2000) who suggests that scholars need to be aware of the western basis of many theorists from the critical theory tradition while acknowledging that these works can support, inspire and help guide alternative anti-colonial initiatives within Aotearoa (New Zealand).

### **19.1 Similarities and differences between Kaupapa Māori and CBPR**

A major difference between Kaupapa Māori and community based participatory research methods is that the conceptualisation of Māori knowledge is located within an oral tradition communicated through Te Reo Māori. In their literature review of Kaupapa Māori principles and practices L. Smith and Reid (2000) outline how educationalists like Tuakana Nepe and Graham Smith view Te Reo as central to a Māori worldview. “Te Reo Māori is the only language that can access, conceptualise and internalise in spiritual terms this body of knowledge. From this, we take it that Māori language and Kaupapa Māori knowledge are inextricably bound. One is the means to the other” (L. Smith and Reid, 2000, p. 3).

While operating from a different metaphysical position there are some similarities in epistemological approach between Kaupapa Māori and CBPR. Scholars working in both traditions view science and knowledge production, not as neutral or value free, but rather as an ideological process. Rather than locating and privileging academic or scientific knowledge, CBPR and Kaupapa Māori researchers often align with a critical theory that incorporates multiple ways of seeing the world. As noted above, Graham Smith (1997) locates points of similarity with critical theory as *conscientisation*, *resistance* and *reflective change*.

However, Russell Bishop (1998) cautions that Kaupapa Māori should not align with participatory approaches. He believes there is a danger in equating the Māori concept of self-determination (tino Rangatiratanga) with participatory methodological approaches. He suggests that to even search for a methodology of participation may risk defeating the central purpose of Kaupapa Māori research, reducing researcher influence on the research process so the research works for the interest of the research participants, each with their own definition of Rangatiratanga. Bishop believes there is a danger in what he refers to as an “international methodology of participation.” He highlights the language of research (objectivity, replicability, validity) and how the use of this language can create space for outside researchers to determine and control what constitutes reality for participants. Bishop argues that even what Lincoln and Denzin (1994) describe as post-positivist frames of reference, as well as the use of non-Māori methodological frameworks, continues a tradition of outside researchers determining what is valid for Māori. Bishop argues that what constitutes a suitable research process and epistemological validity is not determined by the researcher but by the research community in accordance with Māori cultural practices and a Māori framework structuring how knowledge is both produced and represented.

In contrast, Jo Mane (2009) argues that community based research principles should play a greater role in Kaupapa Māori initiatives. She suggests that there is a social, cultural and economic disconnect between the academic discourse of Kaupapa Māori and Māori communities. Mane argues that a danger of Kaupapa Māori is that it is elitist and that Kaupapa Māori approaches are rarely discussed from the position of the community. As a result, many Māori communities have neither heard of or understand Kaupapa Māori. Mane suggests that there is a mistrust of Kaupapa Māori initiatives which could be overcome by directly involving the affected communities in developing research proposals and research designs. Mane says this is necessary because communities know what issues deserve research and they know what initiatives are needed to address local problems through research. Mane identifies a number of similarities between community based research and Kaupapa Māori. Both value research that is driven and led by those directly affected by the issues. Both research approaches can support self-determination and wellbeing. Both validate local knowledge and expertise. Both have the goal of bringing positive change to the community. But Mane also acknowledges a key point of difference; Kaupapa Māori research is produced by, for and with Māori and specifically developed from Māori world views and cultural norms.

## **19.2 Implications for research design**

Wallerstein and Duran (2006) argue that in order to be truly participatory researchers should acknowledge and incorporate indigenous practices, theories and research methodologies. As discussed above there are similarities between CBPR and Kaupapa Māori. However, there are different metaphysical foundations. I am also a white/Pakeha middle class researcher not born in New Zealand and hence very different from the community I am working with. This has important implications for my research design and method that I propose to address as follows.

My research approach acknowledges that the status of Māori health cannot be understood independent of the history of colonisation and the impact of colonisation on socioeconomic and sociocultural development (Durie, 1998; Robson & Harris, 2007; L. Smith & Reid, 2000). An understanding of Māori health cannot be rooted in a western medical model which treats the individual's mental and physical as separate entities. The Whare Tapa Wha Model developed by Mason Durie (1998) conceptualises health as a four walled house with all four elements necessary for ensuring good health. The four dimensions of Māori well being are Taha tinana (physical health) Taha wairua (spiritual health) Taha hinengaro (mental health) Taha whānau (family health).

Dr. Papaarangi Reid (2006) has argued that health promotion needs to be de-colonised and she is critical of a deficit model of health that positions indigenous health as a problem, without acknowledging historical or structural explanations. In a paper reflecting on this commentary and Linda Tuhiwai Smith's observation that the word "research" cannot be separated from European colonialism, three Australian public health researchers engaged in collaborative projects with Aboriginal communities in Victoria, offer some guidance on how to adopt a de-colonising approach to health promotion and research. Pyett, Waples-Crowe and van der Sterren (2008) start with Linda Tuhiwai Smith's (1999) argument that "indigenous methodologies tend to approach cultural protocols, values and behaviours as an integral part of methodology." They suggest that to de-colonise research it is not necessary to invent new research methods, but it is important to place primacy on values, processes, and relationships (Pyett et al, 2008 p. 181). They recommend developing strategies to share power with the participating communities, to take time developing relationships based on mutual trust and shared understanding, and to provide proper acknowledgment and credit to participants. Further, they argue, health promotion interventions need to have tangible outcomes (posters, videos, community reports) that the community actually wants. Most important, they emphasise that the communications focus of research needs to be reversed from a deficit model of health to one that places primacy on

communicating positive stories from the community. Adopting a holistic model of health they suggest can reframe health promotion away from positioning indigenous people as a problem, towards a research approach that highlights community strength and resilience.

### **19.2.1 Indigenist principles**

As Walters et al. (2009) note, many indigenous communities are tired of having no control over the research process and being subject to the whims of “parachute researchers” who drop in to a community, take what they want and quickly depart. Given this historical context, they argue CBPR is an important orientation to research because it builds on local knowledge and culture, emphasises co-learning and decision making, mutual ownership of research and highlights local strengths and resources (Mohammed et al., 2012). In my research approach I am going to apply the eight ‘indigenist’ principles Walters et al. (2009) have developed through their years of working with indigenous communities in the United States. They explain that in addition to drawing on the nine key CBPR principles outlined by Israel et al. (see 15.1) they developed eight indigenous principles because they wanted to not just de-colonise the research process but to re-centre indigenous knowledge. Notably, these principles were developed to incorporate and build on the cultural values and “community-up” definitions of ethical behaviour for researchers outlined by Linda Tuhiwai Smith (2005). I have selected Walters et al.’s principles because they specifically relate to how researchers should work with and reflect on their research relationship when participating in a CBPR project. They define them as:

**(i) Reflection** - examining the privileged statuses from which partners frequently operate

**(ii) Respect** - partners valuing and prioritising indigenous epistemologies, knowledge, cultural protocols, and healing practices;

**(iii) Relevance** - the community should contribute to defining research problems and strategies in response to their own self-identified needs and concerns;

**(iv) Resilience** - all aspects of the research must acknowledge the community’s strengths;

**v) Reciprocity** - the partnership needs to be collaborative and mutually respectful with knowledge exchanged in both directions;

**(vi) Responsibility** - partners are obliged to enhance community capacity to conduct indigenous and Western research, disseminate findings in culturally meaningful ways, and anticipate their implications;

**(vii) Retraditionalization** - traditional knowledge and methods must be integrated actively into the formulation of research questions and the process of scientific inquiry; and

**viii) Revolution** - partners must actively seek to decolonize and indigenize the research process to transform science, as well as themselves, their communities, and larger society for the betterment of all (Walters et al., 2009).

Following these principles should also increase the chances of creating a culturally appropriate digital resource. As previously discussed in the literature review, Gubrium (2009) argues that digital storytelling is an innovative CBPR method that can increase a community's ability to address local health issues. He argues that it is a way for communities to prioritise their own health issues (**relevance**). It is also a way to empower participants to tell their own stories (**respect**). Chavez argues that video can be an effective health promotion tool because it accommodates power differences between researchers, institutions and community (**reflection**) and empowers participants who are not typically engaged in research by creating the opportunity to be heard (**reciprocity**) (Chávez et al., 2004, p. 397). And O'Mara argues that its strength is that it can bring together health workers, community members and stakeholders "in a coordinated approach to community health education that is a reflective, critical and transformative experience for participants" (O'Mara, 2012 p. 2) (**revolution**).

It is important to recognise that CBPR principles alone do not dictate research design and methodology. CBPR is not a method per se (Israel, Eng, et al., 2005b) but an "orientation to inquiry" (Bradbury & Reason, 2003; Minkler, 2004). Subsequently there are published examples employing a wide range of qualitative and quantitative methods (Viswanathan et al., 2004). The variety of methods employed is not a weakness but rather represents a commitment to a participatory research process (Kindon et al., 2008). But Wallerstein and Duran emphasise that CBPR is "not simply a community outreach strategy but represents a systematic effort to incorporate community participation and decision making, local theories of etiology and change, and community practices into the research effort" (Wallerstein & Duran, 2006, p. 314). Israel et al. (2005) explain that "What distinguishes CBPR from other approaches to research is the integral link between the researcher and the researched whereby the concepts of cultural humility and cultural safety are combined with process methods and procedures to establish and maintain the research partnership." (Israel et al., 2005, pp. 11-12).

### **19.3 Role of the researcher: Cultural humility and cultural safety**

A fundamental premise of CBPR is that the research process is neither neutral or value free. Social and political context matters and CBPR researchers need to reflect on the influence of their own power (race, gender, education, class, sexual orientation, religion) on the research relationship (Israel et al., 2005, Wallerstein & Duran, 2008). Chavez et al. (2008) argue that it is not enough to make sure that research questions are culturally appropriate. Rather researchers need to recognise that collaborators often have valid reasons for not talking openly with researchers. As Minkler (2004) explains, researchers should understand that a history of prejudice as well as both internalised oppression and institutional racism may create what Chavez et al., describe as a “dialectic of resistance between outsider research partners and community participants with very real ethical dilemmas in speaking truth to power” (Chavez et al. p. 87 as cited in Minkler, 2004).

Accordingly, leading CBPR academics emphasise the concept of cultural humility in order to address potential power imbalances between researchers and potential community collaborators (Chávez et al., 2008; Israel et al., 2005b; Minkler, 2004; Wallerstein & Duran, 2006). The concept of cultural humility has its roots in medical education (Tervalon & Murray-Garcia, 1998). Tervalon and Murray Garcia argue that researchers will never be able to achieve cultural competence in another’s culture and that subsequently the goal should be to achieve cultural humility. This requires the researcher to participate in an on-going process of self-reflection and critique in which one examines and assesses power relations, bias and racism. It also requires the researcher to be humble, respectful, open, willing to listen and learn, and to be committed to address inequality in the community in which they work (Israel, Eng, et al., 2005b; Wallerstein & Duran, 2006). Israel et al. (2005a) believe that the concept of cultural humility is reflected in CBPR principles, pointing to the promotion of co-learning and the equal value placed on community expertise.

Israel et al. (2005a) also identify the concept of cultural safety as integral to CBPR practice. It has particular relevance to my study given that cultural safety is a concept originally developed in New Zealand in the late 1980s by nurses working with Māori (Ramsden, 1997). Williams defines cultural safety as “an environment that is spiritually, socially and emotionally safe, as well as physically safe for people...It is about shared respect, shared meaning, shared knowledge and experience of learning together” (Williams, 1999, p. 213). As Israel et al. (2005a) acknowledge, for a community to safely participate in research the researcher must first acknowledge the significance of cultural identity and not just political, historical or economic



influencers. It also requires researchers to engage in critical reflection on how factors such as our own language and world view influence our relationship with others (Nursing Council of New Zealand., 2002). Culturally safe CBPR practices include anticipating potential differences with research collaborators and setting up mutually agreed upon processes to resolve issues (Israel, et al., 2005a).

#### **19.4 Who is the community and what constitutes participation in CBPR?**

Jewkes and Mercott (1998) have argued that there is a notable difference between the academic literature and the policy documents of major health institutions when it comes to discussing the meaning and definition of “community.” In the former “community” is contestable and debated; in the latter it is perceived as self-evident. Therefore while institutions like the World Health Organisation and documents like the Ottawa Charter (1987) call for community participation, what is actually meant by this is difficult to define (Jewkes & Murcott, 1998). This is significant given that recognising the community as a unit of identity is a key principle of CBPR (Israel et al., 2003). As MacQueen et al. (2001) have argued, the absence of a commonly accepted definition of community might lead to different researchers developing contradictory assumptions about community which can undermine attempts to evaluate the effectiveness of CBPR programmes.

A 1998 review of health promotion literature found a wide variety of meanings given to the word community (Jewkes & Murcott, 1998). A comprehensive survey of the literature published up to 2004 likewise found that while many definitions of community have been published and operationalised, there is no clear consensus in the health literature (Viswanathan et al., 2004). This is not unsurprising because as Cornwall and Jewkes (1995) point out, communities are not homogenous. Rather they constitute groupings of diverse individuals who might for example, be differentiated by wealth, religion, sexual orientation, and education, to name just a few. This last point is an important one when considering research with indigenous populations. As Linda Tuhiwai Smith (1999) has written, communities do not need to be defined by geography but can coalesce around shared goals and interests. For example, she suggests indigenous communities of interest might include health workers, artists or researchers. Tuhiwai Smith refers to “nested identities” and that people can identify with several different communities. For Māori there are different ways to identify one’s community. For example, a common way of introduction is a mihi that tells people who you are and where you are from by naming the mountain, river, tribal ancestor, tribe and family. As Tuhiwai Smith points out, through the mihi “you locate yourself is a set of identities which have been framed geographically, politically and genealogically”

(Tuhiwai Smith, 1999, p.126). She cautions that native communities are not homogenous and are in fact subject to the same power struggles that perpetuate non-native communities. Gender, age, economic status, education, language and religion can strengthen the positions of some individuals while marginalising and disenfranchising others.

Several scholars have formulated similar definitions of community (Horn et al., 2008; Macaulay et al., 1999; MacQueen et al., 2001; Montoya & Kent, 2011). For the purpose of this study my definition of community is from George and colleagues (1999) who defined community as

any group of individuals sharing a given interest; this definition includes cultural, social, political, health, and economic issues that may link together individuals who may or may not share a particular geographic association. This definition also includes the traditional concept of community as a geographic entity (George, Daniel, & Green, 1999, p. 186).

Israel and colleagues (2008) offer some practical guidance in determining how the community is defined. They suggest asking the following

- Who is the community?
- Who represents the community?
- Who has influence in the community and how, if at all, are they involved?
- Who do the community partners represent---what is their constituency?
- What is the link between all participating organizations?
- How grassroots are the community members/ community based organizations?
- How do the participants compare to members of the community in terms of class (income, education level, gender, race, ethnicity) (Israel et al., 2008 p. 53).

It should be acknowledged that not all CBPR practitioners are comfortable with the types of definition discussed above. Minkler (2004) cites the work of Yoshihama and Carr (2002) who argue that “communities are not places that researchers enter but are instead a set of negotiations that inherently entail multiple and often conflicting interests.” (Yoshihama & Carr, 2002, p. 99). Similarly, Cornwall and Jewkes (1995) observe that definitions of community are influenced by which groups are consulted. They reference Navarro (1984) who argues that a better way of thinking about community is as a set of power relations within which people are grouped. From a practical standpoint, they also acknowledge the dilemma faced by the researcher when determining whether to take a bottom up or top down approach to collaboration. If the researcher

first consults with leaders and prominent groups they gain access to the people who can help create networks but the risk is that those with fewer means are disenfranchised from the process. At the other end of the spectrum, working from the grass roots risks failing to secure buy-in from prominent people and groups and means the research might not get the necessary support and buy-in (Cornwall & Jewkes 1995).

Similarly debate continues not only about *who* participates but also *how* people participate in the research process. In considering what is meant by participation, Wallerstein and Duran (2008) begin with the question posed by Cornwall and Jewkes (1995), “if all research involves participation, what makes research participatory?” To Wallerstein and Duran (2008) the central issue is one of locating where power lies. They encourage the researcher to consider who is participating, for whom, in what spheres, and to what ends? At the same time, researchers must also consider who or what might limit participation. For example, discussing a participatory project with Hmong women, Minkler (2004) notes the reality that in many community projects participation is not stable but often fluid, affected by participants work and family lives and the realities and competing demands of their cultural environments. Drawing on their experiences running CBPR projects, Wallerstein and Duran (2008) similarly observe that different stakeholders often have different ideas about what constitutes participation and the amount of participation might change throughout projects with stakeholder most active in areas that draw on their interests and expertise.

### **19.5 Common Criticisms of CBPR**

As Minkler and Corage Baden (2008) have noted, CBPR research has been criticised by some working in the positivist tradition as not scientifically legitimate research. The authors suggest the critical and action oriented approaches are perceived as antithetical to a public health tradition that has placed primacy on expert based technical knowledge and the pursuit of objectivity and validity. At the same time, the growing popularity of CBPR in the fields of health, development work and policy over the last decade has led to warnings that the principles and ethos of CBPR risks being compromised (Kindon et al., 2008; Minkler, 2004; L. Smith, 2005). Linda Tuhiwai Smith’s (2005) discussion of neoliberal globalisation and the ideology of the knowledge economy, cites the work of Steven Jordan (2003) who argues that even participatory approaches are becoming commodified under a corporate model of education where knowledge becomes a product. Pain, Kindon and Kesby (2007) note there have been postcolonial critiques of CBPR projects in Development Studies by Cooke and Kothari (2001) that argue that researchers, despite claims to the contrary, continue to claim the mantle of experts

by repositioning themselves as experts in participatory approaches. And Minkler (2004) cautions that health research projects are often labelled participatory, where it would be more accurate to call them “community placed” rather than community based.” Greenwood (2002) is particularly critical chastising social scientists practicing action research for being morally superior while being complacent about fundamental issues of theory, method, and validity. He cautions that “doing good” is not the same as “doing good social research.”

In the public health realm, as Wallerstein and Duran (2008) demonstrate, one of the problems with the CBPR literature to date is that a lot of the focus of published research has reported on strategies for creating partnerships, research design, data collection and analysis. There has been a lack of papers on the effects of research interventions on health outcomes and disparities. Building on this argument they cite Viswanathan et al. (2004) whose comprehensive review of CBPR literature concluded that there is still insufficient evidence to prove effectiveness, given that only twelve out of sixty studies reviewed reported health outcome data.

## **20. Research Objective**

As previously argued, there is a need for innovative approaches to diabetes education and prevention that reflect Māori cultural practices in ways that are appropriate for use in Māori communities. Kennedy and Abbatangelo (2004) recommend health communication interventions are specifically tailored from those used for majority audiences. This should include a commitment to formative research that involves members of the target audience from the outset in programme planning. Resnicow et al. (2002) argue that the success of health education materials will depend on culturally relevant design that includes close attention to historical, social and environmental barriers, as well as community norms, behaviours values and beliefs. Community based participatory research (CBPR) encompassing constituent-involving and sociocultural strategies are a fitting methodological approach for health initiatives with Māori. A CBPR approach will reflect the cultural values, behavioural preferences, expectations and environmental context of the participating community (Kieffer et al., 2004).

In this research I will ascertain whether Community Based Participatory Research (CBPR) employed in combination with proven health communication principles and behavioural theory can be used to create a culturally appropriate resource for Christchurch adult Māori at risk for Type 2 diabetes. The research will focus on the community development process of working with an indigenous population to develop a health promotion resource that reflects Māori beliefs

and cultural practices. The remainder of this chapter will be dedicated to an explanation of my multi- method research design.

## **20.1 Research Design**

### **20.1.1 Partnership Development**

Prior to the research commencing ethical approval for the study was obtained from the Health and Disability Ethics Committee (Ministry of Health). Demonstrating consultation with Māori health organisations and relevance and responsiveness to Māori health outcomes were precursors to approval being granted (see Appendix A).

My research design is a multi-method qualitative approach. Consistent with CBPR principles it began with partnership development (Wallerstein, Duran, Minkler, & Foley, 2005). As Kieffer et al. (2005) have documented, researchers need to effectively engage with community organisations and members if they are to develop useful and acceptable community interventions. In this first stage I identified individuals and organisations willing to support or partner with me in a CBPR approach to developing the digital media resource.

I followed the four strategies devised by Wallerstein et al. (2005) for initiating a community partnership. They are

- 1) Self-reflection. This includes thinking about both individual capabilities and institutional ones. What resources do they/I have? What are the potential liabilities? Strengths and weaknesses? What is my position of power vis a vie the research relationship?
- 2) Identifying potential partners. Developing networks, and contacting associations and leaders.
- 3) Negotiating the issue for research. Even if the project is researcher initiated the issues and research questions can be reframed and refined through the partnership.
- 4) Need to continuously think about ways to maintain and sustain partnerships throughout research process .

### **20.1.2 Key Informant Interviews**

Eng et al. (2005) argue that recognising and respecting the issues and priorities identified by key informants is a major CBPR principle. The descriptor key informants is adapted from ethnographic research (Goetz & LeCompte, 1984; Spradley, 1979). Key informants are “those who have been in the community or institution for sufficient time to have accumulated special

knowledge, relationships with people, and access to observations that are denied to researchers” (Eng et al., 2005, p. 88). Interviews with key informants are important because as Eng et al. point out, their understanding of the history and culture of the community and observations on perceived barriers and facilitators for previous health interventions provides a wealth of data for planning and identifying health initiatives. Yet their insights are frequently overlooked in favour of statistical data employed by researchers to identify community needs and health solutions.

At this second stage of the research I interviewed health workers with direct experience working with Māori clients, specifically those with or at risk for type 2 diabetes. They were interviewed to share their perspectives about the Māori cultural understanding of type 2 diabetes including beliefs, risk factors, barriers and facilitators to physical activity and healthy eating. They were asked to help identify whether the documentary resource should target diabetes management or prevention. As important, they were invited to offer their advice and guidance on how to structure the interview guide for the third stage of research, hui (focus groups). This is a significant stage in a CBPR process because as Baker and Motton (2005) observed, what questions are asked of people and the way that they are asked influences what information is acquired and what actions are taken as a result.

Potential interview participants were identified through purposeful sampling. This means identifying a smaller number of subjects that will provide the researcher with an in-depth understanding rather than a large number of participants necessary for generating empirical generalisations (Patton, 2002). Through a strategy described as snowball or chain sampling, local health workers known for their involvement in type 2 diabetes were asked to recommend colleagues who would be appropriate interviewees. Patton (2002) suggests that in most cases a few key names will be repeatedly identified. Sampling is completed when additional interview participants do not provide any new insights.

Qualitative interviewing was a fitting method for this stage of my CBPR study because as previously argued, a CBPR approach should reflect the cultural values of the participating community. Interviewing allows people the opportunity to share their own views and perspectives. As Patton comments, “the purpose of qualitative interviewing is to capture how those being interviewed view their world, to learn their terminology and judgements and to capture the complexities of their individual perceptions and experiences” (Patton, 2002, p. 348). Patton describes three approaches to interviewing and outlines the corresponding strengths and weaknesses: Informal conversational, an interview guide, and standardised open-ended. An informal conversational approach is frequently used in ethnographic fieldwork. With this

approach there are no predetermined questions. The strength of this approach is it allows for a high degree of flexibility and spontaneity. It is particularly useful when interviewing someone multiple times. Potential weaknesses include the possibility that there is a danger of interviewer bias and a body of interviews can be difficult to analyse due to the personalised nature of each interview. An interview guide approach requires the researcher to prepare a predetermined list of topics or subjects areas. This approach is an advantage in that it maintains a focus that makes it easier to compare and analyse a number of different interviews on the same topic. It also provides the interviewer with the flexibility to probe and explore responses and maintain a conversational tone with the interviewee. A potential weakness is the likelihood that some interviews will be more comprehensive than others which might mean analysis is dominated by the perspectives of certain interview subjects. A standardised open-ended interview consists of pre specified carefully worded open-ended questions. Questions are asked in the same way and the same order. This can be an advantage in studies where there are several and/or inexperienced interviewers or where time needs to effectively utilised. This highly focused approach can also make data analysis easier because it is possible to locate each respondents answer to the same question and therefore variation is minimized. The weakness of this approach is that its inflexibility means that it is harder to build rapport with the interviewee and it does not accommodate a spontaneous and potentially information rich change in subject direction.

Patton (2002) explains that these strategies are not mutually exclusive and can in fact be combined. My approach employed a semi structured approach in that I had pre-specified questions and probes. But importantly I allowed for flexibility and spontaneity in the interview to take account of context and the individual interviewee's experiences (Patton 2002). This can require asking the same question a different way or exploring an answer in more depth by asking follow up questions (Israel, Lantz, McGranaghan, Kerr, & Guzman, 2005). I could build a rapport with the interviewees while maintaining a more structured approach that allowed for data analysis that informed the next stage of the research (Baker & Motton, 2005). As Fontana and Frey (2000) have argued, reflexivity is important in order to heighten the researcher's understanding of different ideologies and cultures.

### **20.1.3 Hui (Focus Group)**

After the Key Informant interviews were analysed and interpreted (see Chapter 5) and the focus group questions refined, hui were conducted. As per CBPR principles the direction and focus of the hui was determined in collaboration with community partners. Hui explored and extended the themes identified in the interviews. Beliefs about the causes of type 2 diabetes, personal

susceptibility, barriers and facilitators to physical activity and healthy eating and recommendations for creating a culturally appropriate resource were solicited. The goal of this stage of the research was to generate an action oriented analysis of the community perspective on type 2 diabetes and engage participants in generating ideas for the future direction of the documentary resource.

Focus groups can provide researchers with an in depth understanding of the social and behavioural attitudes of individuals (Stillman, 1992). Focus groups provide more in-depth information than more objective methods like surveys and can be helpful for obtaining the type of in-depth information necessary for the development of culturally specific educational materials (Anderson et al., 1996; Moreno et al., 1997). As Kiefer et al. (2005) have argued, many researchers consider focus groups conducted under the guidance of a moderator to be a culturally sensitive method and particularly appropriate for cultures that value collectivity. It has also been argued that the group dynamic may empower participants by not only encouraging the free flow and exchange of ideas between participants but also potentially impacting the balance of power between the moderator and participants (Madriz, 2000). As with the interview method, participants express themselves in their own words and language (Gettleman & Winkleby, 2000). Kiefer et al. (2005) argue that telling stories allows participants to become “agents of change” as members share perspectives on health and offer strategies to address their concerns that are rooted in the realities of their everyday experiences. Blanchard, Rose, Taylor, McEntee and Latchaw (1999) identified several studies that have utilised focus groups to plan culturally specific diabetes education programmes. One study is particularly interesting. Researchers that conducted focus groups to develop educational videos with African Americans with diabetes found that using the focus group method conveyed a message to the wider community that the health care system valued their opinions and was willing to listen and adapt to the community’s concerns (Anderson et al., 1996).

#### **20.1.4 Digital Resource Creation**

After the hui results were analysed and interpreted (see Chapter 6) production of the digital resource would commence. Because the content of the documentary was to be determined by the direction of the key informant interviews and hui it was not possible at the early research design stage to anticipate the content or approach of the resource. Similarly it was not possible to determine the best behavioural theory to use at this stage. This was consistent with planning a CBPR project. This stage of the research will therefore be fully discussed in Chapter 7.



## **20.2 Evaluation Methods**

### **20.2.1 Process evaluation**

The purpose of this study was to engage Māori health leaders and community members in a participatory process to develop a culturally relevant digital resource for Christchurch based Maori at risk for type 2 diabetes. Earlier in the chapter I explained that I would apply Walters et al.'s (2009) eight indigenist principles throughout my study. These were selected because they specifically relate to how researchers should work with indigenous populations to re-centre indigenous knowledge in a CBPR project. I argued that following these principles should increase the chance of creating a culturally appropriate digital resource. Therefore at the end of the study I conducted a process evaluation to determine how well the principles had been applied. This will be discussed in greater detail in Chapter 8, the evaluation chapter.

### **20.2.2 Procedures for meeting evaluation criteria**

There is continued debate about what constitutes good research and evaluation in CBPR projects. As discussed earlier in this chapter scientific inquiry is frequently structured around positivist research design which is based on a fundamental belief that objective knowledge and universal truths can be studied, revealed and documented. Accordingly, scientific inquiry values knowledge that can be assessed as objective, generalisable, reliable and valid (Lincoln & Guba, 1985; Stringer, 2007). In contrast, in the CBPR tradition, research, science and knowledge production are not approached as neutral or value free. CBPR is inclusive and incorporates multiple ways of seeing the world. Therefore, rather than locating and privileging academic or scientific knowledge, it acknowledges the existence of a plurality of knowledges in a variety of institutions and locations (Fletcher, 2003; Stringer, 2007). As Dew (2007) points out, qualitative research focuses on the social world of subjective realities where understandings of reality are always open for negotiation and interpretation. Some researchers in the action research tradition dismiss the concept of validity altogether arguing it is tied to a positivist position of no concern to the action oriented tradition (Kvale, 1995; Wolcott, 1990). Rather than evaluating qualitative research using terms like validity, Patton recommends using criteria such as “trustworthiness” and credibility.” One of the most widely used set of criteria for assessing the “trustworthiness” of qualitative data are the four measurements developed by Guba and Lincoln (1989). They are credibility, transferability, dependability and confirmability.

**Credibility:** Is the data perceived as credible and believable from the perspectives of those who participated in the study? Guba and Lincoln suggest this can be verified in numerous ways including prolonged engagement (developing trust between researcher and participants), peer debriefings (discussion of findings with other researchers) and member checks (sharing research findings with participants to ensure accuracy).

**Transferability:** Are the research findings detailed in such a way that the reader has enough information to apply them in another research context? Guba and Lincoln recommend providing “thick” description; details not just of methodology but also data about participants and the context in which data has been collected.

**Dependability:** Is the data reliable and could another researcher draw the same conclusions? Guba and Lincoln recommend carefully documenting and describing all stages of the research process including data collection, analysis and interpretations

**Confirmability:** Can the research data be corroborated by others? In order to ensure findings are not unduly influenced by the researcher’s interpretation. Guba and Lincoln recommend establishing a transparent audit trail for the research data and avoiding researcher bias by regularly sharing research data and interpretations with others

As Holcup et al. (2004) acknowledge, Guba and Lincoln’s criteria is important for evaluating qualitative research because by explaining and documenting the method of analysis and creating an audit trail of the data the analytic process can be critically examined. However, as also recognised by Holcup et al. this criterion needs some modification in order to reflect the processes valued and employed in CBPR. For example, while thick description is important, the research *findings* will not be easily transferred to another research context. As Menderhall et al. (2010) point out, CBPR is primarily focused on the generation of local knowledge and producing social change in local communities. Each community will be distinct, unique and complex. What is transferable is the description of the research *process* rather than the findings per se.

Holcup et al. (2004) further emphasise that Guba and Lincoln’s (1989) concept of prolonged engagement will assume more critical importance in a CBPR study given that the relationship between researchers and participants is central to the CBPR process. Most important, they argue that Guba and Lincoln’s focus on methodological soundness, while ensuring rigor, also keeps their approach aligned with the positivist position. Therefore, in order to retain CBPRs focus on the establishment and ongoing development of relationships between stakeholders, Holcup et al.

also recommend drawing on additional criteria. Holkup et al. describe Guba and Lincoln's criteria as follows (Holkup et al., 2004, pp. 170-171).

**Fairness:** The extent to which the perceptions and worldviews of all of the participating stakeholders are requested and respected

**Ontological authenticity:** The extent to which participating stakeholders see their own perceptions and worldviews change or develop throughout the course of the research

**Educative authenticity:** The extent to which participating stakeholders see their understanding of each other's perceptions and worldviews change or develop throughout the course of the research

**Catalytic authenticity:** The extent to which action is promoted by the research process

**Tactical authenticity:** The extent to which stakeholders are encouraged to act

As Holkup et al. point out, while Guba and Lincoln recommend catalytic and tactical authenticity as fitting evaluative criteria for action based research programmes, the criteria cannot effectively address whether a solution was achieved for the identified research problem, whether the project was sustained and most important, whether the participants were actively engaged in all phases of the research. The fact that the last point is not addressed is a significant one as it is one of the central principles outlined by Israel et al. (1998) as a key component of a CBPR research approach. Therefore they recommend adding additional criterion-acceptable problem resolution. I have decided to follow the evaluation process developed by Holkup et al., which builds on Guba and Lincoln's criteria to incorporate the research focus of CBPR projects. I believe their approach is closely aligned with the research interest of CBPR while maintaining a methodological rigour. The criteria are outlined below.

### **20.2.3 Evaluation Criteria**

Credibility, Transferability, Dependability/ Confirmability: **Used to determine methodological rigour**

Level of Community Involvement (incorporates the principles of both catalytic and tactical authenticity): **Used to determine level of community involvement throughout research process**

Acceptable Problem Resolution: **Was a solution to the problem achieved? Was action taken?**  
**Was the created media resource useful?**

Fairness, (ontological authenticity, educative authenticity): **Provides a framework to evaluate how the researcher functioned and worked with members of the advisory team.**

## **21. Final thoughts**

This chapter provided an in-depth discussion of the CBPR model. It included a discussion of the wide range of terms used to define this partnership approach to research and the participatory nature of the approach was emphasised. Background on the theoretical and historical roots of the numerous participatory approaches to research was provided. Epistemological and ontological positions were outlined with the discussion underlining the differences with positivist research. This included valuing experiential knowledge and considering how power operates. An example from my early research discussions was included to illustrate how the liberal democratic view of power often reinforces societal inequalities in health funding. This further reinforced the ontological position of my research in the understanding that science and knowledge production are part of an ideological process and are not neutral or value free. I made an argument for why CBPR is a good fit with Māori and drew comparisons with Kaupapa Māori while also noting important differences. In discussing the implications for my research design I explained why I would be applying Walters et al.'s (2009) indigenist principles. I argued that following these principles should also increase the chances of creating a culturally appropriate digital resource. The concepts of cultural safety and cultural humility were explained and their importance to the process emphasised. Only by adopting both in a process of ongoing self-reflection can the researcher attempt to address potential power imbalances with potential community collaborators. I went on to acknowledge questions about what constitutes community and participation. As part of this discussion I included the definition of community that I adopted. I finished with a brief discussion of common criticism of CBPR. The remainder of the chapter was devoted to explaining the research design.

The following chapter will begin the discussion of the results and is dedicated to a discussion of the community consultation process and the formation of the Community Advisory Board (CAB).

## **Chapter IV. Community Consultation and Partnership Development**

### **Overview**

In this chapter the community consultation process and the formation of the Community Advisory Board (CAB) are explained. The importance of spending time in and gaining the trust of the community are detailed with particular attention paid to the vital role of Kaumatua and “boundary spanners.” Wallerstein et al.’s (2005) four strategies for initiating partnerships are introduced and then specific examples of how this was done are discussed. The remainder of the chapter is devoted to a discussion of the role of the researcher in developing advisory groups followed by a specific explanation of how the CAB was formed. In my final thoughts I discuss the importance of ongoing self-reflection as a critical part of the CBPR process.

### **21.1 Community consultation and partnership development**

In 2001, 21,960 Christchurch residents identified themselves as belonging to the Māori ethnic group (7% of population). According to the 2013 census, the proportion of Māori living in greater Christchurch increased 12.4% between 2006 and 2013, to reach 34,371 (Statistics New Zealand, 2014). Ngāi Tahu is the South Island’s largest iwi (tribe). They hold the rangatiratanga or tribal authority to over 80% of the South Island. Within Christchurch Ngāi Tahu is the most common iwi affiliation (25% of Māori in Christchurch). Other common iwi Māori affiliate to include: Ngā Puhī 10%), Ngāti Porou (9%) and Ngāti Tūwharetoa (4%) (Christchurch City Council, 2005).

### **21.2 Gaining trust**

Israel et al. (1998) have found that lack of trust is the biggest challenge to effectively conducting CBPR research. Gaining the trust and support of community members is the first and most important step in any CBPR project (Shalowitz et al., 2009). The initial contact and the way relationships are developed in indigenous communities is paramount and process is often more important than outcome (L. Smith 1999). Reciprocal relationship building takes time but ensures relationships are respected and the research benefits community members. As Pyett et al. have commented

If we are genuine about including communities in the research endeavour, and if we go about things respectfully and with patience, taking the necessary time to develop relationships of mutual trust and shared understanding, we are

contributing to the process of de-colonising research (Pyett et al., 2008, p. 181).

In particular, Linda Tuhiwai Smith's writing on research ethics guided the early relationship building. As she advises, "the abilities to enter pre-existing relationships, to build, maintain and nurture relationships; and to strengthen connectivity are important research skills in the indigenous arena." (L. Smith, 2005, p. 97). In the same way, Christopher et al. (2008) recommend researchers establish trust with indigenous community members by acknowledging personal and group histories, understanding the historical context of previously conducted research, being present and listening to community members, acknowledging their expertise, and being honest and clear about intentions.

Therefore, at the early stage of the research I made sure that I listened to people far more than I talked. I found that not only did I need to acknowledge personal histories; most importantly I needed to understand collective histories and the close relationships *between* people. In the Māori context relationships are a process built on whakawhanaungatanga (genealogical relationships between people). This was important because the community consultation stage was dependent on face-to-face communication, word of mouth and being on-referred to extended whānau (family) members. Irrespective of the person's standing in the community or the scale of the organisation, they would only talk to me if they had first received a personal referral from someone they knew. Once trust was established, my network started to grow as people referred me on to their extended family members.

Understanding the historical context of previously conducted research was important. Voyle and Simmons' (1999) previous research with Māori revealed community concerns about a history of research with no perceived benefit to the community. A number of candid conversations at this initial stage confirmed that similar concerns were present in the Christchurch Māori community. Concerns were raised by every individual that I spoke with that Māori are too often pathologised and disenfranchised in research studies. In order to gain trust about my research intentions I attended a number of informal and formal forums as well as individual meetings before asking individuals and organisations for support. This included being welcomed on to local maraes and attending community hui. Christopher, Watts, McCormick and Young's (2008) advice to be honest and clear about intentions was invaluable. At a very early stage I was advised by Kaumatua (elders) to never promise more than I could deliver and to honour all promises made.

When I introduced my research proposal there were four additional reasons why the project was well received. First, I had a history and track record of producing collaborative documentaries with Native Americans and Hmong in the United States. Second, I consulted on research design. Third, I was perceived as offering something in return (research reports and a digital resource). Fourth, I spent time getting to know people and building a coalition. Filming did not commence until two years into the research. At this stage all of the key community groups had been consulted.

## **22. Initiating partnerships**

I developed community partnerships guided by the four strategies devised by Wallerstein et al. (2005) for initiating a community partnership. They are

- 1) Self-reflection.
- 2) Identifying potential partners and networks.
- 3) Negotiating the issue for research. Even if the project is researcher initiated the issues and research questions can be reframed and refined through the partnership.
- 4) Need to continuously think about ways to maintain and sustain partnerships throughout research process.

### **22.1 Kaumatua guidance**

My first contact was initiated by a family member with a close working relationship with a local Kaumatua (elder). Māori elders have many important roles in their families and tribes, including preserving traditions and knowledge and providing leadership (Higgins & Meredith, 2013 ). This elder was held in high regard within Ngāi Tahu. We met informally once a month at a local coffee shop. She initiated some meetings and a welcome onto one of the local Maraes (meeting house). Her early mentorship was critical not only in making sure that the research was culturally safe but her mana (prestige) in the wider Māori community safeguarded me at cultural events and meetings where I was unknown to attendees; For example, at a community health hui where I first introduced my research. L. Smith (2005) and Cram (2001) have both emphasised the cultural value of he kanohi kitea (the seen face) as essential when introducing a research project. On a practical level, she offered guidance on how to enter the community, cautioning that this stage could not be rushed. She also opened doors in the community. For example, when I updated her on some problems I was having getting my phone calls returned from a potentially key collaborator she intervened on my behalf. Grateful for previous support the Kaumatua had

offered her, the health worker returned my calls and went on to fully and actively participate in the research.

As important, the Kaumatua helped orientate me towards a Māori understanding of knowledge. As Bishop and Glynn have detailed (1999), a Māori perspective on knowledge is centred in a very different world view from a Western academic perspective. Knowledge is often orally acquired and transmitted and Māori do not necessarily pass on knowledge universally. “Knowledge is a taonga (treasure) handed down by the ancestors and as such is tapu (sacred). Knowledge is expressed in the form of personal power known as mana” (Bishop and Glynn, 1999, p. 171). For example, the Kaumatua spent a lot of her time telling me stories about Ngāi Tahu tribal history, particularly past crown injustices, and the relationships between, and the politics of, different hapu (sub tribes). The significance of these stories soon became clear. As Mason Durie has described in his discussion of interactions on the marae, Māori understanding of time intertwines the past and the future and the future is largely determined by the past (Durie, 2001). Likewise, relationships are governed by histories. This learning also proved invaluable in my later discussions with key informants when a Māori health worker discussed the importance of establishing a relationship through whakapapa with her patients (see discussion in next chapter).

The Kaumatua further advised that I should always remember in my relationship building that with many Māori what is not said is as important as what is. This was important advice to receive at this early stage because it relates back to the discussion of power in the methodology chapter (see Chapter 3, 17.2). As Chavez et al. (2008) have cautioned, CBPR researchers need to recognise that participants often have legitimate reasons for not talking freely and openly. Wallerstein and Duran similarly observe that “people’s assumption of academic research expertise or university agenda may unintentionally hide or silence other voices so that concerns are not directly raised.” (Wallerstein & Duran, 2006, p. 316). The six month time period spent developing the research proposal and learning from the Kaumatua was invaluable. In my early self-reflection memos I was influenced by the advice of Strickland who has described how “The researcher must plan on investing time in establishing working relationships and reading culturally related information and historical documents...developing a humble position of letting the community be the teachers is important ” (Strickland, 2006, p. 234).

Serendipity also played a welcome part at this early stage. Through a personal project I was working on I met another local Ngāi Tahu Aunty with an interest in type 2 diabetes and strong community contacts at a grassroots level. She was to become my greatest guide and confidant.



As someone who had direct experience working with diabetes education and outreach her background knowledge was critical. As Fletcher (2003) has advised, it is pragmatic to understand how research has been previously conducted and recognise what attitudes might be to university research or other external agencies. Further, with her direct experience in the community she could serve a vital role as a “boundary spanner.” Kelly et al. have described how at the initiation stage of a CBPR project it is essential to find a liaison person who can help determine whether the subject is important to the community and how it should be approached (Kelly, Mock, & Tandon, 2001).

## **22.2 Ngāi Tahu endorsement**

Both the Kaumatua and the Aunty helped facilitate an introductory meeting with Sir Mark Solomon, Kaiwhakahaere (Chair) Te Rūnanga o Ngāi Tahu where I outlined my research approach and gained his verbal (later written) support to pursue the research. He also made recommendations of other community members and groups to contact (see below). This endorsement was significant as it constituted consent to initiate contact with community groups and He Oranga Pounamu, a Ngāi Tahu mandated organisation that services the wider Māori health and social service networks and whānau across Canterbury. I met with a representative of this organisation and secured an invitation to introduce my research at a community consultation hui attended by many community health providers.

The presentation at the community hui was my first opportunity to introduce the research to a large number of people working in Māori health. I had been cautioned that presentations by Pakeha researches had not always been well received. As a result of this advice I took specific steps to increase the chances of acceptance. First, I had visible support from Kaumatua who attended. Second, I could demonstrate with visual examples that I had used a similar approach with previous documentary work with Native Americans. Third, I requested feedback on the research focus and design and offered to provide regular updates on the research. After the presentation food was served and I had an opportunity to informally network with the attendees. Those I spoke with expressed a strong desire for a diabetes prevention resources rather than management. This need was also reinforced at the next stage of research with the key informants. The hui was also an ideal forum to solicit additional names of people that should be consulted on the research proposal and/or interviewed for the next stage of the research.

At this juncture further self-reflection was required. Most CBPR researcher will face a similar dilemma in determining whether to take a bottom up or top down approach to collaboration. By

first consulting with leaders and community groups it is possible to gain access to the people who can help create networks but the risk to the researcher is that those with fewer means are disenfranchised from the process. At the other end of the spectrum, working from the grass roots up risks failing to secure buy-in from prominent people and groups and sometimes means the research might not get the necessary support (Cornwall & Jewkes 1995). Because Ngāi Tahu is so instrumental in the provision of health services and because I was new to the community, I determined that early support from leadership was critical.

### **22.3 Te Kāhui o Papaki Kā Tai (TKOP) support and the Christchurch District Health Board**

The Aunty next initiated contact with two Māori women with experience in the health fields and a long history of grassroots community involvement. I met with them both informally over coffee and outlined my approach. Both women had family histories where diabetes was prevalent. One of the women, who is diabetic, expressed personal frustration with the printed materials currently in circulation. Both women were supportive of the research design and in turn organised a formal introduction to a group they were members of -Te Kāhui o Papaki Kā Tai (TKOP), a joint Māori health advisory group.

TKOP is a Canterbury-wide combined group of representatives from primary care organisations, clinicians, community organisations, Māori health providers and the District Health Board. I was invited to formally present my research proposal at a meeting and again secured initial support to proceed. This group later became instrumental to the research. Two members joined the community advisory board and other members contributed either as research participants or by making recommendations for people to interview. One of the members later identified people to participate in the documentary. Two of the members were affiliated with Primary Health Organisations (PHO) that provide Māori Health Services. In turn, both PHOs became important supporters. At a later stage they offered financial support to help get the documentary made. One of the Māori health managers became a key member of the advisory group and both Māori health workers participated in on-camera interviews for the documentary.

The Christchurch District Health Board was another important sector to liaise with. I met with a team leader from Nga Ratonga Hauora Māori/Māori Health Service who suggested I meet with the Māori diabetes nurse and community health worker as well as members of the Māori Community and Public Health teams. At these meetings, these individuals also confirmed the research and resource creation were necessary. They later became instrumental in supporting the

research as both members of the Community Advisory Board and leaders of the hui (focus groups).

#### **22.4 Additional support**

In order to secure broad support and be reflective of the community, it was also important to approach Māori not affiliated with Ngāi Tahu. A number of the community organisations and people I met with were located in Aranui, close to Nga Hau E Wha National Marae, the largest national Marae in New Zealand. Te Runanga o Nga Maata Waka became a key location for social services after the Christchurch earthquake when a number of Māori organisations set up on the Marae after they were displaced due to structural damage. I was invited onto the Marae by a trustee and Kaumatua who was friends with my father in law. He had personal experience with type 2 diabetes and offered his assistance. He became another significant supporter serving as a key adviser and participant in the documentary.

#### **23. Summary: Refining the research approach**

Some CBPR scholars have argued that the community must always define the research question and that a significant element of CBPR is a commitment to making sure the topic under investigation is initiated by the community (Minkler, 2004; Stoecker, 2008). However, as Reason (1994) has observed, many CBPR projects are still developed by individuals with the time, expertise and commitment and this is typically someone from a privileged or educated group such as a university researcher. In a review of the CBPR literature, Minkler and Corage Baden (2003) found that some researchers who first defined the research question still revised and modified their problem statements after consultation with the community. Other CBPR practitioners have developed guidelines outlining how the research focus can be refined through a collaborative process (Mercer et al., 2008). Minkler (2004) has concluded that even topics initiated by outside researchers can still become “owned” by the community and that once this occurs a research project can reflect a community’s concerns.

Accordingly, at the first stage of the research it was important to ascertain how my research focus might need to be revised or refined based on community consultation. For example should the media resource focus on prevention or management? Were key informant interviews and community hui the best research method for soliciting information? A consensus quickly emerged that there was a strong preference for a prevention resource. This was probably because many of the people I initially consulted were very aware of the diabetes statistics for Māori. And

as the next stages of research quickly confirmed, there are few families that remain unaffected by this disease. The participatory model was also welcomed by many of the people I consulted for offering a chance to avoid cultural misunderstandings that had undermined some earlier health promotion initiatives. For example, I was told about a previously produced resource that prominently featured an owl. Seen as a symbol of wisdom in Pakeha culture, in Māori mythology the owl can represent death. Moreover, the opportunity for key informants to advise on the questions for the hui was favourably received. Finally, the CBPR model is flexible enough to accommodate modification. For example, it later became clear that the hui should be divided by gender and led by CAB members rather than me. This adaptation yielded richer and more sensitive data than sticking to the original research design.

### **23.1 The importance of time**

The community consultation process and partnership development stage cannot be rushed. I had to spend time getting to know people and building a coalition. Filming did not commence until two years into the research. This was consistent with the wider literature on successful community engagement. As Shalowitz et al. have found success is contingent on “developing an understanding of the cultural values, the formal and informal family networks, the formal and informal patterns of communication and communication in groups is part of the process and it takes time” (Shalowitz et al., 2009, p. 353). In the remainder of this chapter I will describe how the Community Advisory Board was conceptualised and initiated.

## **24. The role of the researcher**

Graham Smith (1992) describes four models for non-indigenous researchers to produce culturally appropriate research with Māori; The *tiaki mentoring model* where the researcher is guided by well-respected Māori; *whangai adopton model* where the researcher is fully immersed into the daily life of the community and becomes one of the whanau completing the research; *power-sharing* where the researcher requests assistance from the community to support the research and the *empowering outcomes model* where the research addresses the questions that Māori want to know.

Stoecker (2008) has described three roles commonly assumed by CBPR researchers. The *initiator* approach is where the researcher generates a research project with the goal of handing control over to the community. Stoecker cautioned the problem is that the researcher maintains an authoritative position assuming that he/she knows what is ‘good’ for the community. The

*consultant* role typically occurs when a community group commissions a researcher to carry out research on its behalf. While the researcher is accountable to the community, Stoecker cites John Gaveta's (1993) critique that there is still a separation of power and knowledge between the researcher producing the knowledge and the community most affected by it. The third role is the one that I adopted for the research. This role sees the researcher as a *collaborator* with the community. The researcher offers their technical expertise and the community leaders their knowledge of community needs. Stoecker has cautioned that true collaboration is difficult to achieve and he questioned whether it goes far enough in generating new knowledge.

Stoecker (2008) further advised that academic researchers conceptualise their work as a social change project which requires that four roles be filled. They are leader, community organiser, popular educator and participatory researcher. *The leader* is an indigenous community member with excellent communication skills who demonstrates a willingness to learn from others. The *community organiser* is a community member who can help the research team and community plan, act and evaluate. The *popular educator* helps community members and researchers think about the issues, often in new ways. As Stoecker cautions their role is not to transfer their personal knowledge and expertise to the community, but rather facilitate community members to articulate and express their own knowledge and understanding of an issue. The *participatory researcher* facilitates the research process, provides technical skills and is committed to democratic participation in the research process. One person can occupy several roles or several people might occupy the same role.

Stoecker's CBPR researcher model and Graham Smith's models have similarities in how they conceptualise culturally appropriate research (collaborator/power sharing model). The models were helpful when initiating partnership development and refining the research focus in consultation with the community. For example, as described earlier it was essential for me as a non-Māori researcher to be guided by well-respected Māori (Smith's tiaki mentoring model and what Stoecker calls a leader in a social change project). I adopted the participatory researcher as collaborator role. Next I will describe how the CAB functioned and what roles were filled.

## **25. Community Advisory Board (CAB)**

In considering how to organise the Community Advisory Board (CAB) I was guided by Bishop (1998). Bishop recommends a research approach based on the concept of whanaugatanga (togetherness). As Bishop explains, whanaugatanga is one of the fundamental ideas within Māori culture and he describes it as both a value and a social process. It guides one on how to establish

and maintain research relationships and orients the researcher to understanding that their research requires ethical, moral and spiritual involvement. I followed Bishop's recommendation to establish a research group like an extended family, what he calls a 'whanau of interest.' Meetings should begin with a karakia (prayer) and the sharing of food. Decisions should be made as a group and approved by Kaumatua. As Bishop explains, "Research thus cannot proceed until whanau support is obtained, unless Kaumatua provide guidance, and unless there is aroha (mutuality) between the participants, evidenced by aroha overriding feeling of tolerance, hospitality, and respect for others, their ideas and their opinions" (Bishop, 1998, p. 204).

In thinking about who to approach to serve on the CAB I looked for people that could fill the four roles described by Stoecker. As a participatory researcher I would provide my research skills and technical expertise as a filmmaker. I approached the Kaumatua from Nga Hau E Wha National Marae to serve as a leader, the Auntie I met at the very beginning of the research to be a community organiser, and Māori health workers representing the DHB and local PHOs to serve as popular educators. The CAB comprised of eight members and also included a Maori doctor and someone with extensive experience in Maori health strategy. We agreed that

- Everyone's views were to be solicited and respected
- All analysis would be discussed with the CAB in order to ensure accurate interpretations and to avoid harm
- Results would be put into a community report and not just academic journals
- The created resource would build on and highlight community's strengths and be relevant and acceptable to the community
- The CAB members would help facilitate access to facilities, networks, people, knowledge

As previously explained, I am not undertaking Kaupapa Māori research and I would again clearly acknowledge that there are epistemological differences in CBPR and Kaupapa Māori conceptions of knowledge. However, I believe the whanau of interest approach is applicable because as Bishop (1998) has commented, it is driven by a research process that is participatory and participant driven. The whanau's interests and preferences drive the research process. As described later there are examples of this in both the key informant and hui stages of research. Further, how Bishop conceptualises the role of the researcher shares similarities with Stoecker's (2008) description of the CBPR researcher. The researcher is not there to "empower" the other. Rather they are part of a collective and Kaumatua guide culturally appropriate procedures for

decision making (Bishop 1998). Further, employing the whanau of interest model goes some way to ensuring the indigenist principles of reflection, respect, relevance and reciprocity are followed.

## **26. Final thoughts**

As discussed throughout this chapter, self-reflection is an important part of the CBPR process. In relation to the CAB I was guided by Wallerstein and Duran's (2006) work discussing how power shapes relationships and L. Smith's (1999) discussion of power issues within contemporary indigenous communities. These writings serve as a reminder that it is important to acknowledge that each individual that makes up the team comes with a set of privileges and position of power that shape their thinking and interactions with the group. Each of us might be in the dominant group in some domains but not in others. For example, I was in the dominant group in terms of education but not in others (age, gender or language). Recognising this was beneficial to the research. For example, as Chapter 6 on the hui research will later explain, separating the discussions by gender and having them led by Māori members of the CAB ensured that participants would speak more freely than they would have to me as a Pakeha university researcher.

This chapter emphasised the importance of allowing time in reciprocal relationship building with the community. For the researcher it requires listening and being honest and clear about intentions. Kaumatua support is also integral to gaining entry into the community. Once relationships are initiated, it is important to be cognisant of collective histories and relationships between people, especially when whānau connections are key to expanding networks. Researchers should try to recognise formal and informal patterns of communication and also remember that due to past injustices, people will sometimes be reticent to speak their minds. Offering something in return also increases the chances that research projects will be favourably received. The exchange of knowledge must flow in both directions. Finally, Stoecker and Bishop both offer models for the formations of CABs that serve as useful and instructive guides for building successful research partnerships.

In the following chapter I will describe and discuss the findings from the key informant interviews. Community understanding of diabetes, common misconceptions, barriers and facilitators to healthy eating and exercise will be explored. The CAB's vital role in shaping the analysis will be underlined. The discussion will highlight similarities with historical research findings while broadening this debate beyond statistical data. Honouring the primacy on

community participation key findings will be illustrated by supporting quotes. A discussion of service delivery barriers will also illustrate the need for CBPR researchers to remain flexible with their research design.



## **Chapter V. Key Informant Interviews**

### **Chapter Overview**

Resnicow et al. (2002) argued that the success of health education materials will depend on culturally relevant design that includes close attention to historical, social and environmental barriers, as well as community norms, behaviours, values and beliefs. Accordingly, the purpose of the interviews described below was to develop a better understanding of Māori beliefs about diabetes in order to develop the foundation for a culturally appropriate digital resource. I will begin the chapter with an overview of the research process and how the data was analysed. I will then describe the key findings and illustrate them with supporting quotes from the interviews. I will discuss the important role the CAB played in analysing the findings as well as highlight the early implications the results had for shaping the documentary messaging. The chapter will conclude with a description of how and why the key informants helped shape the questions for the next stage of the research.

### **27. Key Informant Interviews: Purpose and approach**

Interviews with key informants were important because their understanding of the history and culture of the community provided valuable information for planning the documentary. Key informants were interviewed to share their perspectives about the Māori cultural understanding of type 2 diabetes including knowledge, beliefs, risk factors and barriers and facilitators to physical activity and healthy eating. The key informants who participated in the interviews represented a number of stakeholder groups including the Christchurch District Health Board (CDHB), General Practitioners, and Māori service providers. Participants were recruited from General Practice, nursing, referral services (diabetes specific) and health promotion. Interview participants were identified through purposeful sampling. The Community Advisory Board (CAB) helped identify nurses, whānau and community health workers with direct experience with diabetes prevention and management or Māori health promotion. Two GPs with a high number of Māori enrolled as patients also participated. Each interview participant was asked to recommend colleagues who would be appropriate interviewees. As anticipated, a few key names were repeatedly identified (Patton, 2002). A total of twelve interviews were completed.

Potential interview participants first received an information sheet that outlined both the overall purpose of the study and the specific goal of the key informant interviews (see Appendix B). Those who agreed to an interview then signed a consent form that outlined the purpose of the

study, the risks and benefits to participation including confidentiality and how data would be used to inform the next stage of the research (see Appendix C). All interviews were conducted *kanohi ki te kanohi* (face to face) at the participant's place of work. All interviews were audiotaped and transcribed verbatim. Participants were given the opportunity to review and edit their transcripts for fairness and accuracy.

After the member checks were complete, the transcripts were stripped of identifiers and the first stage of coding completed. As the interviews utilised a semi structured approach and the same questions were asked of each participant, data could first be simply coded according to the interview questions (see Appendix D). Miles and Huberman (1994) describe descriptive coding as a way to organise and summarise data as it requires little inference. This approach was employed in order to facilitate partner analysis of the results. As Cashman et al. (2008) have found, in many CBPR studies communities are not typically involved with data analysis. This might be due to time constraints, particularly the need to develop the appropriate knowledge or expertise (Israel, Lantz, McGranaghan, Kerr and Guzman, 2005). But as these researchers argued, it is essential that partners be involved in interpreting the data. Israel et al. (2005) emphasised that it is essential that results are fed back in ways that are both understandable and useful. Cashman et al. (2008) have recommended engaging community partners' involvement with the analysis by displaying data in easily understood formats like coded transcripts. Consequently, I wrote a report in non-academic language to be shared with the Community Advisory Board that grouped interviewee's responses according to answers. I also made some initial observations that could be used to generate discussion and analysis.

Meetings were then held with the Community Advisory Board to discuss the initial findings. As not all CAB members could meet at the same time, a separate meeting was held with two of the members. In line with CBPR principles, the meeting was a mutual and respectful exchange of ideas and understanding. As Forbat and Henderson have argued (2005) the co-analysis of interview transcripts can strengthen analytical rigor and researcher reflexivity and generate strong research relationships. For example, CAB expertise was essential in negotiating an in-depth understanding of barriers to physical activity and healthy eating (see following discussion). As a group we reviewed the transcripts and identified the following major themes from the interviews

- Prevalence and Impact of Diabetes
- Causes of Diabetes (Including Misconceptions)

- Diabetes Care and Service Delivery
- Diabetes Education
- Barriers to Healthy Eating and Physical Activity
- Solutions: Ways to Facilitate Healthy Eating and Activity

It was agreed that I would then refine these topics into a thematic analysis with supporting quotes as part of my PhD write up. At the same time, the CAB would share and discuss the initial report with their constituents in the community for possible feedback. For example, the observations about service delivery barriers might prove helpful to local PHOs.

The second cycle of coding was pattern coding. Miles and Huberman (1994) describe pattern codes as explanatory or inferential. It is a more interpretive approach used to develop major themes, patterns, causes and explanations from the data. At this stage I used Atlas ti. Software. I reviewed the similarly coded passages from the community report that were coded by question and developed pattern codes for each of the major topic areas identified with the Community Advisory Board. A code book was developed with basic code definitions (see Appendix E). A follow up meeting was held with the CAB and the results presented. Each member was asked to confirm the accuracy of the interpretation and make recommendations for change where necessary. The results of this analysis are presented below. Key themes are also presented in Table 1 following this analysis.

## **28. Prevalence**

There was a consensus that type 2 diabetes is a huge problem in the local Māori community and that it is probably under reported. Most interviewees expressed the belief that there are many Māori with undiagnosed diabetes and who have not visited a GP in at least the last year. These observations are substantiated by the CDHB quantitative data on Māori health in Canterbury (Reid, 2010). There was a similar consensus that many of those already diagnosed with type 2 diabetes were not making the necessary changes to manage the disease. As one Doctor commented.

*My general sense is it's a lot bigger than what's recorded. I think people understand diabetes is on the increase but I'm still coming across people who haven't seen a GP at least in the last year sometimes even longer, five years. But it's huge. Even the population that I'm working with most of those have diabetes or are pre diabetic.*

One community worker expressed a sense of powerlessness at the enormity of the problem.

*The outcomes are shocking. I've been through my book and you get to the list of our patients in alphabetical order, and I've got so many deceased, deceased, deceased...I've never worked so bloody hard in my life and I feel I've achieved nothing sometimes because there are so many dead that I've looked after.*

### **28.1 Diabetes as a whānau experience: Fear, grief and denial**

It is common for Māori diagnosed with diabetes to have at least one whānau member with the disease. Because they have seen the results first hand, key informants reported that some Māori patients express the desire to manage their diabetes as they are fearful of developing similar complications. Said one.

*There are not many Māori families who have not experienced losing a whānau member from diabetes. They usually know someone who is on dialysis, or has been on dialysis, or has lost a limb.*

Whereas some patients have used their observations of whānau as a positive motivation for their own diabetes management, it is far more common for Māori patients to exhibit fear or denial when facing a diagnosis of type 2 diabetes. Key informants observed that their patients see diabetes as a death sentence rather than a disease that can be controlled and managed with the proper care. In most instances this appears to be because patients have directly observed a close family member suffering from diabetes related complications. So common was this observation that the CAB identified addressing this misconception as a key message for the documentary resource. As one nurse commented.

*There's lot of grief goes with diabetes. I think it's a sense of death sentence and I think there's a lot of denial goes on because of that.*

This comment was mirrored by another nurse.

*If they have seen family die from diabetes that's also part and parcel of the "I don't want to know" or the "I've been there and I know all about it." They really don't want to face it... it's I know that one day I'll end up on insulin so in the meantime I'll just enjoy myself.*

Gender differences were also evident. Key informants observed that women are typically frightened at diagnosis because they assume diabetes automatically means injecting insulin: Men are often in denial. One of the interviewee's expressed particular frustration with her male clients who she described as thinking of themselves as "ten feet tall and bullet proof."

*I tell them straight up I say you could bloody die if you don't look after yourself, and they say 'she's full of kaka.' I said to one yesterday if you don't listen you're going to be dead. He said, 'well then I'll be dead then. Because nobody tells me what to do!'*

## **28.2 Misconceptions about cause**

All of the key informant's observed that there are low levels of diabetes knowledge and awareness in the Māori community, particularly as it relates to cause. As one doctor observed

*I think what I've found is that a lot of people don't realise that being above their healthy weight is definitely a very high risk factor of getting diabetes.*

Likewise a nurse commented that

*There probably isn't, and this goes for non-Māori as well, there isn't that understanding of the lifestyle aspect and the impact that that has.*

These findings are consistent with previous research (De Lore et al., 1993; Kirkwood et al., 1997; Simmons & Voyle, 2003). The most commonly identified misconception is that diabetes is caused by consuming too much sugar. As a result, the CAB identified a need to address this common misunderstanding in the documentary messaging. The following quotes illustrate the prevalence of this belief.

*The first thing they say is, oh I must've eaten too much sugar eh? That's what they say! Nothing about the lifestyle. They don't realise it's the lifestyle. You get answers like I used to have five sugars in one tea.*

*We had one gentleman who'd been told not to eat sweet things and lollies anymore and that's what he thought was all he had to do. But they didn't tell him about the Kentucky Fried and the Fish n Chips. He was only forty seven when he died.*

## **29. Barriers**

### **29.1 Barriers: Economic**

A widely discussed theme was the economic barriers preventing Māori patients and community members from accessing medical services and medications. One interviewee said she could identify three or four people who should be seeing a podiatrist but were not because they simply could not afford to. As part of this discussion interviewees also noted that even transport to

medical facilities often presents its own set of challenges, with many patients unable to afford the cost of a bus fare or gas for the car. Coupled with the cost of a doctor's visit and prescription, diabetes management was identified as a luxury many patients simply cannot afford. One doctor has experienced this many times commenting

*I think Māori fall through the cracks in many ways. It could be I don't have any money to get the medicine this week so I won't bother.*

High unemployment presents its own set of challenges to good health; Depression and low motivation were identified as barriers to eating well and exercising. A community health worker explained how financial constraints are particularly noticeable during winter months.

*...in the winter it's horrific because there's a big juggling of do I buy power or do I buy food? I can't really afford both. So which one do I buy? Do I buy power and go warm and not have food or do I buy the food and freeze? You know there's a lot of juggling because the rent takes up the majority of the wages. Sometimes there's only twenty thirty dollars left. Once I said to do a budget and they said you need money to budget! How can you budget on twenty dollars? You can but it's not realistic.*

Interviewees' comments substantiate well documented barriers to healthy eating. Many patients struggle meeting basic needs (rent, power etc.) which leaves very little income for food, let alone healthy options. Cheap food is often unhealthy food and is perceived by many of the key informants as being heavily promoted by powerful advertising. Although key informants noted that many of the people they work with understand basic nutrition, cost is the biggest mitigating factor to healthy food purchases and a practical constraint that limits food choices. As one nurse noted

*People are smart though aren't they? No one wants diabetes and if grainy bread is better than white bread they really want it. But hey if you've only got two dollars left and the brown one is four then you don't have much choice.*

A similar observation was made by another nurse.

*We are in a world full of easily procured foods, just go down the supermarket and buy whatever you want. Usually all the foods that are not good for you are cheaper than the food that is healthy, for example, soft drinks as opposed to milk, white bread as opposed to wholemeal/grain bread and so on. For low income people cost is the deciding factor when purchasing food.*

An additional complication was caused by the effects of the Christchurch earthquakes.

*The diet, I mean particularly for us here in Linwood probably is influenced a bit by costs and I mean it is expensive. Countdown reopened a couple of weeks ago but you know until then to get somewhere that sold fresh fruit and veges was quite a trek and if you haven't got a car that's a huge barrier.*

Advertising was also discussed as having an impact on food purchases and in the promotion of diabetic products. Said one community health worker

*I always check it out what they say and it is. It's cheaper to buy Coca-Cola than buy water. Water costs you two three dollars. Or over two dollars. Coke you can get for ninety nine cents half the time.*

Another nurse expressed frustration at the marketing of diabetic product ranges.

*There is no such thing as a diabetic diet. That's rubbish. But why would you pay twice as much for a pack of diabetic biscuits? It's companies making money out of people's ill health.*

At the same time the supermarket experience was perceived by one community health worker as part of a larger lifestyle change with specific cultural implications.

*Our natural means of eating was gathering food as a whānau or communal activity. Not only is the traditional food gone or polluted, our way of life has changed and is no longer passed on to our grandchildren. We were actively participating in gathering food from the sea, waterways and land. Changes to lifestyle have occurred for many New Zealanders, we no longer live off the land; we live off the supermarkets.*

## **29.2 Barriers: Cultural**

Key informants suggested that one of the biggest challenges for weight control is the culturally accepted thinking that "big is good". The cultural expectation remains that a good host will provide guests with a lot of food. One nurse believed that many Pakeha dieticians were failing to recognise that food is an expression of manaakitanga (hospitality).

*Our people think in terms of big is good. So large quantities of food on the plate. So it's changing that thinking the manaakitanga. There's that cultural aspect that you would never want someone to leave your home and say oh well they didn't feed me much. Oh that wasn't very nice. So you have that expectation that you will feed them well and they will leave feeling full and they*

*will leave feeling happy and sustained and you will feel good because you've managed to contribute that.*

One key informant described the cultural barriers non-Māori health professionals might encounter when trying to discuss food choices. She gave the example of her Māori patients just laughing when advised to create a healthy boil up by first trimming the fat from the meat.

*You know they're going to be looking like you've lost all your marbles honey because that's the best part. They are on such different planes. Their wavelengths are just so not there. And people say to me you know from a cultural perspective what do you think's happening? And I say well you know you are not thinking like them.*

### **29.3 Barriers to exercise**

Barriers to exercise include lack of confidence and self-esteem, shortage of time, lack of motivation and the perceived financial cost. One key informant explained that their promotion of free Ministry of Health resources like Green Prescription met with little success.

*I'm being told oh no it's too cold, it's too dark. So there's quite a resistance there at times.*

To address the lack of self-esteem in female clients one of the key informants initiated a local swimming programme that allows women to choose their own outfits to exercise in.

*If we said you must be in a bathing suit we wouldn't get anyone because they wouldn't feel comfortable. And already their confidence and self-esteem is low. These are some of the things when you say to our whānau you've got to go exercise they look at you as if to say I can't.*

### **29.4 Barriers: Diabetes services**

The biggest topic of discussion was service barriers. There is a history of Māori not engaging in diabetes services. In a follow up email, one of the key informants expanded on her discussion about why this occurs.

*The reason whānau workers were established was to bring our Māori people into the diabetes clinic for reviews. It was difficult to understand why people were not coming in when the service was free of charge and especially because they had the best diabetes specialists in one place.*

She went on to list a number of reasons they had identified about why Māori did not attend.



- Were overwhelmed with the regiment like environment
- Did not see other Māori - felt whakama (embarrassed)
- Many were younger than European patients - some had children
- Were minority in diabetes education classes
- Felt inferior in biology knowledge so would not ask questions
- Felt staff at centre were not approachable.
- Doctors' fees – cost
- (Medical staff) Attitude. Were arrogant
- Transport
- Lack of confidence
- Lack of understanding clinical jargon
- Not being able to follow Doctor's direction about healthy food

#### **29.4.1 Distrust of health services**

Distrust of health services was detailed by several key informants. This can have implications for effective health and disease management. As one community health worker observed

*With the doctors and the nurses no matter how wonderful or how knowledgeable or how good they are, our people sometimes have that perception of mistrust. So they will just sit there and go 'yes, yes', without thinking about the real answer. Or just give you the answer they think you want to hear. Whereas if I gave the same questions, they would think about it, they would talk about it; They would talk about their whānau and their experience. That would all come out because they trust us.*

#### **29.4.2 Communication problems**

Significantly there was a noticeable communications gap between medical professionals and their Māori clientele. Key informants attributed this to the prevalence of the use of medical language.

*It is common for all organisations/entities because we all have our acronyms and identifying language, and health professionals are no different. We expect people to understand biology, not realising that many have not had the opportunities of a good education.*

One whānau worker recounted an experience of taking an elderly client to a doctor who attempted to explain the function of the pancreas in diabetes care and management.

*... And he left the room and she looked at me and she said, ' what's a pancreas dear?' She wouldn't ask the doctor because she felt at her age she should know and she didn't want to let the doctor think she didn't know.*

As discussed later in the chapter there is a contrast between the westernised biomedical approach to health care and the more holistic model implemented by some of the Māori health professionals. One of the key informants who emphasised the importance of whānau and whakapapa (genealogy) in treatment expressed surprise at how some of her non-Māori colleagues communicated with patients.

*Traditionally people in education just look at the here and now and then move forward, nobody ever explores what brought you to this point? And I hear the girls and I think crikey you gotta have a foundation and they just bowl in and blurt out, so this is what you **need** to know. But I haven't actually asked you what do you **want** to know, because they are not the same.*

Another interviewee noted that health professionals can nag or belittle a client while at the same time being unaware that the individual has a lot of mana (influence and prestige) within the Māori community.

*When you ask people why they don't turn up to appointments, they say it is because they are afraid of being reprimanded like children because they have not lost weight or they have not managed to give up smoking or they had not kept good records of their sugar levels and so on. Some of these people are held in high esteem by their hapu, iwi because of their knowledge in Māori - something which is unknown to health professionals.*

Notably several key informants identified dieticians as a particular group of health professionals their clients did not want to see. One expressed the belief this was because goals were set too high for her clients.

*The feedback from clients is that it's just too much. It's really strict to the point where they just go I can't do that so I might as well not do anything.*

Another commented on the tone of delivery.

*I still think that it's negatively geared. Everything about diabetes is negative. If you see a dietician you can't eat this you can't eat that. You can't do this and you can't do that. It's not positively geared enough.*

An interviewee recalled giving a non-Māori colleague advice that positive encouragement should be given for the most incremental of changes.

*'ll give you an example. I took \_\_\_\_\_ she's a dietician, a lovely girl. And this man we visited had lost 200g. And she said, 'oh, you've only lost 200g' I took her aside and I said celebrate that he hasn't put weight on. And he was looking at her and going she's a dietician and she's skinny, what does she know? From then on she did and she was fantastic and he's actually lost about 6 kg.*

### **29.4.3 Racism**

Some key informants recalled negative experiences with non-Māori colleagues. One discussed a response from a colleague when she asked her to present to Māori patients.

*She asked me if there would be one of those "welcome" things, and as long as she could come with me, and I didn't leave without her, she would come. It still astounds me that we have lived in this country, together, for over 150 years and these health professionals still didn't know us.*

Other key informants identified institutional racism as the reason for the disparity between Māori and non-Māori health. One Doctor commented

*It does make me wonder at times whether there is a bias towards Māori people or whether there's a bias upon race, or the squeaky wheel gets more oil? The people who are more informed make more noise. They are more likely to get better care which normally goes with being better educated, which normally goes with being more Pakeha European than Māori.*

A similar sentiment was expressed by another Doctor.

*Socio economic factors are a statistic that is used when it suits. Once funding is identified most organisations make use of it with a token attitude if it is the "brown" dollar. I am not convinced that funding is spent appropriately for Māori because the national health statistics for Māori have not changed.*

## **30. Solutions: Diabetes services-holistic.**

There was a marked contrast between how some key informants perceive the role of GPs, specialists and dieticians and their own roles (whānau workers and nurses). They are a pathway between medical services and the community. One health worker described the difference as follows:

*I guess it's the emotional side for my approach. Doctors cannot show too much emotion, hence the term 'clinical', because that is what is needed. I believe you absolutely need whānau workers who are not nurses, not social workers, but the person who supports you when you have a medical problem or a chronic condition, and you need to deal with your emotional or spiritual needs.*

One nurse believed a more patient centric approach was required.

*If it doesn't start at a patient perspective there is absolutely no point. And quite often we'll find that we get brought in later down the track once the problems have occurred. Well if you'd got us in the first place, if you'd just rung us in the first instance we could have avoided all of this and now we've got to turn this around?*

Many described a more holistic approach to patient care and this included elements of Te Whare Tapa Wha. The quotes below reinforce this point as well as illustrate how prevalent this position was among key informants.

*You can educate people till the cows come home but it may not be enough. You need to look at them a bit more holistically.*

*They don't know what it feels like and the varied feelings that go with diabetes. Not just physical but the mental, spiritual, the whole aspect of the whole person is affected by diabetes.*

*The medical people come from the physical. When dealing with Māori people ones that know about their tikanga the protocols, they come from a more holistic position. Any education should be holistic. That's my suggestion.*

*[Te Whare Tapa Wha] I swear by that model and our people know that. They love the model because it covers out tikanga, our protocols. It covers all over. It helps to understand better, it helps to build that rapport, that trust between us. It helps to put the spiritual side in which is very important to our people. It helps to identify who they are and who we are and why we are here. It helps with all the different areas of their health too.*

There was a contrast between the clinical medical focus on the individual (see service barriers discussion) and the approach taken by the interview participants, a holistic emphasis on the whānau. One key informant told me she does not even mention the word diabetes in the first couple of appointments. Rather she establishes whakawhanaungatanga.

*We establish links within our whakapapa. And when you have often they go 'oh I'm your Aunty we're related' And of course you now get buy in because all of a sudden you are now my niece and not a health professional that is sitting there with a big head and letters after your name. Now you are whānau, so what have you got to say?*

Another interviewee distinguished between the biomedical definition of successful treatment as regaining independence and the more collectivist Māori approach. She told me that her approach is to always think of the patient in relation to whānau, hapu and iwi (family, sub tribe, tribe).

*When we admit someone into hospital we are ultimately working so they can regain their independence and resume their activities prior to admission. But when you are looking at our people it's never about the "I", it's never about the individual and independence. It's about the bigger picture and we use the word inter-dependence with whānau. So it's not about independence, myself, it's about how I can get back and look after the whānau?*

The more holistic approach has service delivery implications as acknowledged by one of the key informants. She compared her diary to Pakeha nurses and noted that she will see half the amount of patients as the Pakeha nurse on the same day. When questioned about it by her bosses she told them that a thirty minute appointment is not adequate for a Māori patient when at least twenty minutes of that time will be needed to enquire after the whānau. She recounted her follow up discussion with administrators as follows.

*But the thing is that you want our people to engage in a service and yet you are going to dictate that service before they even arrive? So I'm going to say to you this is the service that I believe is most beneficial to their wellbeing, not what's most beneficial and most cost effective and how many you can see in a day.*

### **30.1 Solutions: Realistic goals and expectations**

In contrast to the observation that many dieticians' approaches were too negatively focused, the key informants who were nurses distinguished their approach as a pragmatic one. They described taking incremental steps and limiting the number of health messages they conveyed at one time. One nurse described an approach that she had found successful.

*I might look at whether they're having a whole lot of takeaway foods and try to reduce that by one night a week, even though that's not ideal and their diabetes is going to get worse, it's better than being unrealistic and saying well you can't have any.*

## 30.2 Food

Key informants had practical strategies for educating patients about healthy and affordable food. They were mindful of budget but also prepared to make the argument that basic groceries do not need to be expensive. One common response was about limiting the amount of takeaways for both financial and health reasons. These two illustrative quotes reflect a key message that was later included in the documentary.

*For what it costs to take four children and two adults to McDonald's that's half your groceries for the week if you were eating basic foods: Vegetables, meat, fish, bread and cheese.*

*And this is the message we are trying to get to our people. Keep it simple. You don't need to go to MacDonald's to have a burger. You can get some meat and make your own burgers.*

## 30.3 Exercise

All of the key informants interviewed were familiar with patients' objections to introducing exercise. These included lack of time, money and motivation. A common theme that emerged was that that exercise does not have to be expensive and does not need to involve costly equipment or gym fees. The interviewees encouraged what one termed "accidental exercise."

*I'm always about accidental exercise. I try and help them to identify that they are already doing things in their lives that is exercise, they just didn't know. So doing the gardening, doing the washing. So it's about being personalised and fitting what's happening for them. It has to be real. It can't be you need to come and do this! That's not going to work.*

Another key informant explained that staff members try to be positive role models to the community.

*Currently right here and now we have a nutrition and fitness programme running. Every morning we come in and try to be examples of healthy eating. We are eating breakfast together so we can all support each other. We all go and exercise together.*

Several interviewees emphasised the importance of activities tailored for women with low self-esteem and body image.

*There is no restriction on what they must wear. So they wear tights down their ankles and shorts down to here. They must be lugging a lot of weight in the water but they have a level where they*

*can be comfortable. If we said you must be in a bathing suit we wouldn't get anyone because they wouldn't feel comfortable. And already their confidence and self-esteem is already low.*

### **31. Health promotion resources**

Key informants were also asked about their current use of educational resources to facilitate discussions and understanding with clients about type 2 diabetes. Several commented that pamphlets were of limited use.

*I can't even give pamphlets to them because they just give 'em to the kids and say here let them draw or else they throw them straight in the rubbish.*

A key theme was that the new resource should feature the stories of real people who have experienced diabetes.

*Māori like to hear things rather than read things...Patients that are suffering from diabetes and how it's been for them. Their stories. That's the best way to learn.*

*I would listen to someone else that had experience of it rather than a doctor. He knew it medically. He was treating people and seeing the consequences. But he doesn't know what it feels like to have that condition.*

A related theme was that the real people should also be positive role models imparting an important message to the community. The following quote encapsulates this theme and much of the approach that informed the documentary messaging.

*I think if I saw a video that said stand tall, be proud, learn whatever you can learn I would want to watch it more because videos for me have to have something that I get something from. Not just about the subject but why I'd want to carry on watching it and learning from it. If our Māori people could see some humour, things that they can identify with, especially if they're overweight, and see that we are who we are and delight in our differences. However, for the sake of our mokopuna we need to take note of the health professionals if we want to be around to see our mokopuna grow up. Remind us of who we were and the food the healthy food that sustained us. Encourage us to support our children with the knowledge we have gained from having diabetes and the pitfalls that lead us to this condition.*

A key theme was that the role models should be people that community members could easily identify with.

*I think the first thing that comes to mind is a resource that the individual patient can identify with...I think having someone they can identify with will make it more real to them.*

A related theme was that the documentary messages should be whānau (family) focused.

*Many Māori families are big. For me it would be about health eating messages for the family and not just then individual. Not making them feel like it's just for you because you've got diabetes. It needs to be inclusive. It would be about a life change for the family knowing that the family would potentially be at risk of diabetes as well.*

**Table 1. Key informant interview themes**

<b>Prevalence Impact and awareness of Diabetes</b>	<b>Illustrative Quote</b>
Prevalence	<i>It's huge. Even the population that I'm working with most of those have diabetes or are pre diabetic</i>
Whānau Experience	<i>There are not many Māori families who have not experienced losing a whanau member from diabetes.</i>
Fear	<i>People are fearful of having it because they've seen what can happen with poorly controlled diabetics relatives, especially with Māori.</i>
Grief	<i>There's lot of grief goes with diabetes.</i>
Denial	<i>I think it's a sense of death sentence and I think there's a lot of denial goes on because of that.</i>
Misconceptions	<i>The first thing they say is, oh I must've eaten too much sugar eh? That's what they say! Nothing about the lifestyle.</i>
<b>Barriers to Eating Healthy and Exercise</b>	
Financial	<i>I think Māori fall through the cracks in many ways. It could be I don't have any money to get the medicine this week so I won't bother.</i>
Mental Health/Depression	<i>When people are depressed they don't look after themselves.</i>
Cost of healthy food	<i>No one wants diabetes and if grainy bread is better than white bread they really want it. But hey if you've only got two dollars left and the brown one is four then you don't have much choice.</i>
Social Marketing	<i>It's cheaper to buy Coca-Cola than buy water.</i>
Cultural	<i>Our people think in terms of big is good. So large quantities of food on the plate.</i>
Time	<i>Exercise is more of a time thing in terms of I've got so many other commitments, where do I fit this in and how do I do it?</i>
Low Motivation	<i>I'm being told oh no it's too cold, it's too dark, so there's quite a resistance there at times.</i>
Low Self esteem	<i>When you say to our whānau you've got to go exercise they look at you as if to say I can't.</i>



<b>Diabetes Care and Service Delivery</b>	
Distrust	<i>With the doctors and the nurses no matter how wonderful or how knowledgeable or how good they are, our people sometimes have that perception of mistrust before they come in.</i>
Poor communication	<i>There is a definite “medical language” known only to the medical profession.</i>
Unrealistic goals	<i>It's really strict to the point where they just go I can't do that so I might as well not do anything.</i>
Negativity	<i>Everything about diabetes is negative. If you see a dietician you can't eat this you can't eat that.</i>
Racism	<i>Once funding is identified most organisations make use of it with a token attitude if it is the “brown” dollar.</i>
<b>Solutions</b>	
Holistic care	<i>You can educate people till the cows come home but it may not be enough. You need to look at them a bit more holistically.</i>
Te Whare Tapa Wha	<i>I swear by that model and our people know that. They love the model because it covers out tikanga, our protocols.</i>
Collectivist	<i>It's not about independence, myself, it's about how I can get back and look after the whanau.</i>
Small steps	<i>I might look at whether they're having a whole lot of takeaway foods and try to reduce that by one night a week.</i>
Affordable food	<i>Keep it simple. You don't need to go to MacDonald's to have a burger. You can get some meat and make your own burgers.</i>
Accidental exercise	<i>I try and help them to identify that they are already doing things in their lives that is exercise, they just didn't know. So doing the gardening, doing the washing.</i>
Communal support	<i>We are eating breakfast together so we can all support each other. We all go and exercise together.</i>
<b>Goals for Health Promotion Resource</b>	
Real people	<i>I would listen to someone else that had experience of it rather than a doctor.</i>
Positive role models	<i>If our Māori people could see some humour, things that they can identify with, especially if they're overweight, and see that we are who we are and delight in our differences.</i>
Easy to identify with	<i>I think having someone they can identify with will make it more real to them.</i>
Whānau Focused	<i>For me it would be about healthy eating messages for the family and not just then individual.</i>

## 32. Discussion

The key informant interviews reinforced data from quantitative studies documenting low levels of diabetes knowledge and awareness in the Māori community (De Lore et al., 1993; Kirkwood

et al., 1997; Simmons & Voyle, 2003; Wyllie, 2009). Co-analysis with the Community Advisory Board yielded some significant insights. As CBPR has a goal of practical action one important theme that emerged from the interviews was service barriers and the multiple reasons that Māori do not utilise available health services. The CAB drew particular attention to interviewee's discussion of the numerous service delivery barriers preventing Māori from successfully engaging with health services. This observation is significant because Pakeha society tends to emphasise individual lifestyle choices as central to good health (Hodgetts & Chamberlain, 2000). The New Zealand media has also been found to downplay racial explanations, emphasise personal responsibility and to ignore questions about levels of health care and services for Māori (Hodgetts et al., 2004). Māori engagement with health services was characterised as one of distrust, poor communication, negativity and institutional racism. Too often blame is apportioned to those expected to respond rather than a critical examination of the services themselves. For example, the results suggest that health providers should consider longer appointment times for Māori clients. Some key informants explained that time was necessary for the process of *whakawhanaungatanga*, an observation also made in a 2010 diabetes study with Maori in the Waikato province (Blundell, Gibbons, & Lillis, 2010).

Notably, these results also reinforce previous research that shows a long history of culturally insensitive health services for Māori (Simmons, 1996; Smith & Pearce, 1984). These findings are a good example of how CBPR researchers need to remain responsive to community needs. While the discussion of service providers had no direct bearing on the content of the documentary, the findings could have some bearing on future policy decisions. As a result the findings were shared with local PHOs in the hope they would inform the debate about how to best work with Maori to improve health outcomes (see Appendix-J Cartwright letter).

As I have previously argued, there is a need for health promotion materials that recognise and engage with the social context that effects racial and ethnic inequalities in health (Nazroo & Williams, 2003). Poor dietary choices and lack of physical activity need to be considered not just from a biomedical perspective, but also in the context of the established cultural norms in which diabetes is experienced and understood. This point was reinforced by the key informant interviews and the CAB's analysis. While key informants sometimes expressed frustration at their patient's decisions, they situated their noncompliance within a framework of economic, cultural and social barriers that impede people's ability to prevent or manage type 2 diabetes. The contrast between the biomedical model and the Māori health model is a fitting illustration of this point.

In the literature review, I argued that effective communication interventions are needed to address the disconnection between medical professionals' biomedical perspectives on type 2 diabetes and the cultural and experience based beliefs that influence how Māori might understand diabetes. The interviews with the key informants made clear that the biomedical model can indeed be a poor fit for Māori with diabetes. Key informants noted how medical language and jargon create communications difficulties between medical professionals and Māori patients. They described a more holistic approach and this included elements of Te Whare Tapa Wha. In contrast to a western model of care situated in the here and now, these nurses and whānau workers described a model of care where exploring the past and whānaungatanga was central to their care plan. In the case of one of the interviewees this meant not even mentioning the word diabetes in the first meeting.

### **32.1 Implications for documentary messaging**

The historic, economic, cultural and social explanations for the high rates of type 2 diabetes and the lack of compliance with care in the Māori community had early implications for the documentary messaging. Some potential messages and approaches to the documentary started to take shape at the analysis stage. So common was the observation that Māori perceive diabetes as a death sentence, rather than a disease that can be controlled and managed with the proper care, that the CAB identified addressing this misconception as a key message for the documentary resource. Likewise, the CAB felt that the common misconception that diabetes is caused by consuming too much sugar needed to be further explored in the next stage of research. It was agreed that we would explore the barriers to healthy eating and exercise with the hui participants to see how their responses reinforced or possibly contradicted those of the health professionals interviewed. Finally, we decided that some of the solutions offered by the key informants (incremental steps and small changes) might be key messages conveyed in the documentary. The key informants call for positive messaging, real people and positive role models would also become a key component for the documentary. This was significant because these findings mirrored my analysis of successful components of health promotion campaigns with Maori (see literature review). By respecting, valuing and prioritising community knowledge and protocols, deeper networks were established. For example, several of the key informants offered to help recruit for the next stage of research. Explaining her interest in the research one of the interviewees stated.

*You see we've never been asked that simple question, what would we like to see in a film? We don't get asked as Māori.*

### **33. Hui (focus group) guide**

The next stage of the research was hui with Māori about their beliefs and attitudes related to type 2 diabetes. Understanding beliefs is critical to intervention planning. Beliefs about the cause of diabetes, personal susceptibility and risk, may influence motivation to undertake change. Moreover, as previously discussed, Resnicow et al. (2002) argued that the success of health education materials will depend on culturally relevant design that includes close attention to historical, social and environmental barriers, as well as community norms, behaviours values and beliefs. Yet there is scant published literature on Māori knowledge or beliefs about diabetes.

CBPR paradigms for data collection recognise that the questions asked and *the way they are asked* influences the information gathered and thus the actions taken as a result. It is therefore important that any interview guides or questions make sense to, and are useful for, all partners and participants. For this reason, the key informants were asked to advise on the structure and wording of the hui questions. I also requested their opinions about the best way to obtain relevant information about knowledge and beliefs. In addition, they were asked to help identify culturally sensitive ways to conduct the hui. During the interview the key informants were shown a rough draft of potential questions and asked to comment on the structure and wording. Modifications were made accordingly. Questions were then further modified to explore and extend the themes that emerged from the key informants interviews. A copy of the revised questions was then sent to all of the key informants for final feedback (see Appendix F for questions and suggested revisions). Questions explored understanding of diabetes and barriers and facilitators to healthy eating and physical activity.

In the following chapter, I will discuss the results of the community hui and how the joint analysis reinforced the key findings from the key informant interviews. The hui generated in-depth data about perceptions of diabetes, historical, social and environmental barriers, and community norms and values. After providing pertinent illustrations I will discuss how this data also had significant implications for the documentary messaging.

## **Chapter VI. Hui Results**

### **Chapter Overview**

Internationally few studies have focused on the perception and lay understanding of diabetes in indigenous populations or the social and cultural meanings of the disease (Boston et al., 1997). The same is true in New Zealand. In the previous chapter, key informants were interviewed to share their perspectives about the Māori cultural understanding of type 2 diabetes. In this chapter, I will describe the results of hui designed to further explore how Māori cultural beliefs and values might influence health beliefs and behaviours. Building on the results of the key informant analysis, the hui aimed to gather pertinent data to inform the following stage of research, the production of the documentary. Key themes from the data will be described and potential messaging for the documentary identified.

### **34. Hui: Purpose and approach**

Hui (focus groups) are a fitting way to obtain in-depth information. They are a culturally sensitive method where participants can express themselves in their own words and language and share perspectives rooted in the realities of their everyday experiences (Kieffer et al., 2005). Beliefs about causes, personal susceptibility, whānau experiences, as well as barriers and facilitators to physical activity and healthy eating were explored.

Participants were recruited through formal and informal channels. I first contacted all of the Māori health providers initially approached at the partnership development stage and asked them to extend an invitation to all of their members. This was done through email and by verbal announcement at community events. The Community Advisory Board (CAB) and some of the key informants also utilised their professional and social networks. Most of this recruitment was completed face-to-face and additional follow up completed in the days leading up to the hui to ensure attendance. Potential participants first received an information sheet that outlined both the overall purpose of the study and the specific goal of the hui (see Appendix G).

In the chapter on community consultation and partnership development I explained that an important part of the self-reflection process was acknowledging that all CAB members would have a set of privileges and a position of power that shaped their thinking and interactions with the wider group. Each of us might be in the dominant group in some domains but not in others. When the research design was originally conceptualised I planned on leading the focus groups. However, it quickly became apparent that my position as a Pakeha female academic researcher

could well impede open conversation. As one of the key informants commented early in the process

*And dare I say one of the first thoughts that came into my head is how they would even take the message from yourself being female or being English with the accent. There could be long held colonial barriers or beliefs. You know what do I want to listen to this person for? I mean who knows there may be somebody with the wahini that may say I ran into this tall slim English woman where we are shorter brown faced and rounder and she's talking to us about being active?*

Discussion with the CAB confirmed that the best way to honour cultural expectations and facilitate discussion was to have members of the CAB lead the hui groups, especially as two of the facilitators themselves had type 2 diabetes. Moreover, they were all well respected within the community. As important, the decision was also made by the CAB to separate groups by gender in order to encourage frank and open discussion. We also separated groups according to whether or not participants had been diagnosed with type 2 diabetes. Again this was seen as a way to encourage open discussion. At the same time it also made it possible to assess whether there were any significant differences between the groups.

I met with the facilitators prior to the hui to review the interview guide questions and research needs and ethical protocols. The CAB also advised that it was important to build in additional time to accommodate Māori custom and protocol. For example, sharing food as an expression of Manaakitanga (hospitality) is critical to ensuring the trust of participants in a research setting. It was important the hui also functioned as a social occasion; an opportunity to discuss family and the emotional and spiritual aspects and health and wellbeing. It was agreed that the facilitators would follow the interview guide but were free to put the questions in their own words and in an order that would facilitate conversation.

The hui were held at the Whānau Tautoka conference rooms, a well-known and easily accessible location. On the day of the hui a member of the CAB verbally explained the kaupapa (purpose) of the study and led a karakia (blessing) to start the meetings. Participants then signed a consent form that outlined the purpose of the study, the risks and benefits to participation including confidentiality and how data would be used to inform the content of the documentary resource (see Appendix C). As is customary, kai (food) was also served. Offering food is critical to ensuring the trust of participants in a research setting (Blundell et al., 2010). Koha (a gift) in the form of a voucher was also provided to each hui participant.

Three of the sessions had nine active participants, and one session had eight active participants. The women with type 2 diabetes ranged in age from 37-67. The women not diagnosed ranged in age from 18-37. Men with diabetes ranged in age from 18-67 (with one reporting age 67+). It was the same demographic profile for men not diagnosed. The sessions ran for approximately 90 minutes. At the end of the session participants were asked for feedback on the discussion process. The interviewers summarised what they believed to be the key ideas to emerge from the session at which point participants were invited to respond. The four sessions were videotaped and then transcribed verbatim. After the data was analysed for key themes, participants were given the opportunity to review, revise and confirm the findings.

Descriptive coding was first applied to the data. As with the previous analysis, organising the transcripts according to question was a way to display and share the research data with the CAB in an easily comprehended format. I also created summary tables that could be used to generate discussion with the CAB (see Appendix H). The results were again summarised in a community report. As before, a meeting was held and we discussed the research as a group. The CAB shared this initial report with interested constituents in the community and given the continued discussion about service barriers, copies were also provided to local PHOs.

At this stage of the research having read the community reports, three PHOS and Ngāi Tahu indicated that they would offer financial support for the creation of the documentary. This was seen as a positive sign that the research was progressing in a culturally appropriate way. As with the key informant analysis, the second cycle of coding was pattern coding where the codes and major themes identified from the key informant analysis were further developed. A follow up meeting was held with the CAB and the thematic results presented. Each member was asked to discuss the accuracy of the interpretation and make recommendations for change where necessary. The results of this analysis are presented below. Key themes are also presented in Table 2 following this analysis.

### **35. Knowledge and experience of diabetes prevalence**

All of the key informants had previously observed that type 2 diabetes is rife in the communities they serve. The hui discussion substantiated these observations. All four groups: females with type 2 diabetes (FWD), females not diagnosed with type 2 diabetes (FND), men with type 2 Diabetes (MWD), and men not diagnosed with type 2 diabetes (MND), had at least one whānau member living with diabetes. Many participants discussed multiple members of the family with the disease. The following represents a typical statement expressed on the day.

*Diabetes was always going to be a thing. My brother and his son have diabetes. My father, my grandmother, and they didn't even have medication in their day. My sisters and I have five brothers. The two sisters who are older than me they have diabetes.*

But even in families where the disease was rife this did not translate into an understanding of cause. As one female with diabetes commented

*When they first told me I had diabetes I had no understanding of it. I mean most of my whānau have died from it. My grandmother lost a leg. Then my mother developed it. My grandfather had it and my father had it also. My sisters also have it. I've got ten sisters and five brothers. None of my brothers have it but just about all my sisters have it.*

There was a notable difference between how the groups with and those not diagnosed with diabetes made sense of the family experience. Those with diabetes discussed their own diagnosis with a sense of fatalism. Diabetes was expected and seen as inevitable in light of their family history; It was perceived as a hereditary condition.

*We grew up in ignorance because we didn't know what diabetes was or what caused diabetes. We just knew, well the thing in our family was well you're going to get it one day. It's going to hit you. So it was an expectation that we just got it. I grew up thinking like that.*

Those not diagnosed did not express the same expectation that they would get diabetes although their family experiences were often quite similar. However, it cannot be determined whether this is an actual difference or rather a way for people with diabetes to rationalise the diagnosis.

### **35.1 Causes, symptoms and prevention**

As the preceding section demonstrated, direct family experience with diabetes does not translate into an understanding of causes, symptoms, or ways to prevent the disease. Of the two groups of people with diabetes no one had been aware of causes or symptoms prior to being diagnosed. As one participant recounted

*FWD: I thought I will never get diabetes. My mum used to say to me 'why don't you think you'll get it when everyone else has got it' I said 'well I don't drink'. She said 'well it's not necessarily the alcohol that you have'. I said, 'I might have a wine now and then but I love my kai (food)'. She said 'I know you love your kai'. And I said I have the love of my whānau so no, I'm not going to get it. So when I did actually develop diabetes I had absolutely no understanding of it whatsoever.*



These findings also substantiate previous academic research documenting low levels of diabetes knowledge and awareness in the Māori community (De Lore, Hamilton, Brown, & Lunt, 1993; Kirkwood, Simmons, Weblemoe, Voyle, & Richards, 1997). One man with diabetes also mentioned a historical confusion about cause, perhaps as a key informant had previously observed related to an old education campaign that used to refer to the disease as “sugar diabetes.”

*MWD: I've had diabetes since 1999 and when I first got it there was a misconception around saying that it was sugar diabetes. So I thought oh well I'll stop taking sugar and that will cure me. Well I got a rude awakening. That wasn't the case. And it wasn't until I associated myself with a clinic and the girls here that I realised how bad the disease was amongst our race.*

When the MWD group were asked whether they were aware of causes or symptoms men prior to being diagnosed they all said no. A couple of men offered that they had associated the symptoms of diabetes with getting old.

*MWD: I think that the symptoms that I was becoming aware of I sort of associated with growing older...I noticed that I was progressively getting slower and feeling more pains but I kept saying to myself and possibly fooling myself, hey that's part of getting old...So it's really interesting to be here and hearing amongst ourselves. Now I can go hey that's part of diabetes.*

Similarly, the MND group could not identify any symptoms of diabetes. However, this was the only group to make an explicit connection with exercise as a preventative measure. A few of the men made a connection between diabetes prevention and exercise.

*MND: For me, I exercise every day but the food I eat it's pretty crap. But I exercise enough at the moment to keep it going but if I ever got injured or anything like that like I have in the past...I keep eating like that and put on a lot of weight. So if anything like that happened it would be a snowball type of effect.*

These comments were interesting in light of the experiences discussed by two of the men with diabetes who because they exercised considered themselves less susceptible to illness.

*MWD: You know I never thought there was such a thing as diabetes because when I was diagnosed I had never heard of it. I used to be a fitness freak. I used to run up hills and run for miles every day and I thought there is something wrong as I was getting slower and slower and tireder and tireder. And yet I was fit. And I didn't know that I had diabetes. It actually came by*

*accident how I found out. I went to a Marae, all the Māori people were asked to come to a Marae. And they all went down and they started having tests and I thought well I'd better have a test too. Well they tested me and I was really mad when I found that out.*

As I reviewed and reflected on the interviews I recognised that having CAB member lead the hui not only encouraged open conversation it also provided a forum for education and support. Some of the men with diabetes discussed meeting again to provide support to one another. Both facilitators of the groups with non-diagnosed participants used the discussions as an opportunity to not just learn from the participants, but also to provide them with information about the disease and correct common misconceptions. This was an appropriate and ethical response. As one man commented

*MND: I'm naïve. I don't really know about it and I know of people that have diabetes or have been affected by it but that's as much as I know. I think that naiveté is a slap in the face now that I need to know about it.*

Because both facilitators were also educators and well respected in the community the hui provided a welcoming forum for diabetes education. This is significant because a key principle of CBPR is the reciprocal exchange of knowledge (Israel et al., 2001).

### **36. Experience of diabetes: Fear and denial**

When the two groups with diabetes were asked about their experience living with the disease there was a clear gender difference between the two groups. Women with diabetes focused on their fear of needles.

*FWD: I hate it (injecting) but I still do it. And I'm still in denial because I'm going to reverse it! And I'm truly informed so it's not like I don't know the story.*

The frank discussion in the men's group provided further evidence that dividing the groups by gender and having them led by a man with diabetes strengthened the quality of the research data. Men with diabetes discussed their frustrations with losing their physical fitness and being susceptible to infections. Impotence was also discussed. This links back to an observation made in the key informant interviews that men do not want to believe they are physically vulnerable. And as key informants had previously identified, there is a strong element of denial regarding the diagnosis.

*MWD: Yeah it hurts you doesn't it? It hurts you here. You feel you are bullet proof.*

In a frank exchange one man reflected on just how much his life had changed.

*MWD: I don't want to sit and stare at four walls. I want to work. I used to be a painter. I had to give it up. I used to be a security guard and had to give that up through diabetes. Once it starts to attack you it doesn't stop. It attacks my eyesight. It just shuts you down all over the place. I'm forty nine. I haven't had sex for two years.*

For the women not diagnosed their expressed fear about diabetes was directed primarily at their husbands' health.

*FND: I was with a group of women two days ago and we were moaning about our husbands...and it happens when you get older because when you get older you fear that they are going to die and I'm a bit nervous because of his puku (stomach) but you say you need to do it yourself. But then you end up doing it for them because you think he might die on me! So that's all to do with diabetes because it touches on real fear.*

### **37. Health**

Hui participants primarily focused on the role of whānau in maintaining good health. The overwhelming response from all group members to the question *what does being healthy mean to you?* was staying healthy for the sake of the mokopuna (grandchildren). The quote below was typical of the responses.

*MWD: First off, I've got grandchildren and I want to be associated with my grandchildren and I can't do that if I am sick. That's important to me.*

A Māori understanding of health was also expressed by one of the participants, reinforcing the key informants' observations that a holistic approach is important in diabetes care.

*MWD: Being healthy is not just medical. If you're Māori it's spiritual. It's whaiora. It's everything Māori that we do and we need our whānau on board to be healthy. We need them to be on board and to walk that walk with us. They need to make the changes. That to me is healthy. Healthy to me is you can look at exercise and kai but it's also about the whānau also.*

One participant discussed health in relation to Māori cultural beliefs about death and dying.

*FWD: Māori have a different concept about death and dying. You know right up until about five years ago I had my funeral planned. Everything was in place and it was okay for me to die because I know where I am going to and who I am going to see. So it was never a big issue about*

*me dying. Except for my favourite moko, I've got ten of them and a great grandchild, but I decided I actually really want to be around at their twenty-first and how do I do that without changing something? So it about my moko. But in the same respect dying is not a big issue for me and I think that's a Māori thing. Am I right in saying that? (Women voice agreement) We look at it differently.*

The younger male participants also said it was about looking good and feeling confident. The FND group did not specifically answer this question. This was probably because the direction of their conversation tended to focus more on their concerns for their partners than concerns for themselves.

### **37.1 Physical activity**

Men with type 2 diabetes (MWD) had a long discussion about how the concept of exercise has evolved historically and they were nostalgic about their upbringings. As one participant commented

*MND: I remember when we were young we were quite active. Alright there wasn't a lot of the technology, Play Station things like that. But also I personally think we were safer back in the day. The cars weren't fast so your parents used to say get out and play on the road! And there was a park. We lived on the edge of Northcote School and there were paddocks. You'd go out and do whatever you'd want. Go down the stream and play and try and cross the rivers. You'd be out and about and you'd be walking around. Nowadays I don't know if I'd let my kids go outside and even bike to school these day. Gymnastics? Karate that's organised once a week? It's not the same is it?*

A similar comment was expressed in the MWD group.

*MWD: I think one of the things that stands out is if I think back on our people and we go back pre-Pakeha contact. People used to run for forty miles, have a fight and then run home for another forty miles! Now even to go down to the shop is an effort. We get into the car to do it.*

While most of the men in this group had once been physically active, only one man said he was presently engaged in sport. This was probably the biggest difference between the MWD and MND groups. Every participant in the MND hui was physically active.

One of the females with diabetes was familiar with what one of the key informants had termed “accidental” exercise. To her, exercise was kicking her legs back and forth on a chair while

sedentary. Only one female in either group participated in a regular form of exercise; Everyone else was sedentary. A number of explanations were given for why participants should exercise. Older participants both male and female again expressed a desire to be present for, and physically capable of, handling grandchildren. The comments below are representative of the views expressed.

*FWD I said I don't want to die not yet. I want to see my mokos get married. I want to do something about it, so I exercise.*

*MND: I guess another reason for me is the fact that I have three new moko coming through and at some stage I'm going to have to take them out for a play in the playground and I want to be able to handle that.*

A range of explanations were offered as to why participants did not exercise. They included cost, tiredness, time, laziness, lack of motivation and earthquake disruption. Participants with diabetes also cited the physical limitations and stress of living with the disease. Notably, while the key informants were more likely to stress environmental and socioeconomic barriers to physical activity and nutrition, men in both groups were more likely to express the view point that good health is ultimately an individual behavioural choice and a reflection of one's personal motivation and will power. As one of the younger participants stated

*MND: I reckon it's basically you as person whether you want to do it or not...The whānau has an influence on you. But it still comes down to you as a person whether you are going to walk in the door or not. You can be dragged in but it's whether you are going to stay or not?*

A possible explanation for this might be dominant societal norms that emphasise individual lifestyle choices (Hodgetts & Chamberlain 2000). Family history might also influence this perspective. One young man expressed exasperation at his whānau for not making changes.

*MWD: I've lost too many close whānau that should still be alive. It was their choice to be lazy, to be indulgent whatever. They just didn't do the work they needed to do. My aunties have died at fifty, many close whānau that should still be alive. It was their choice to be lazy, to be indulgent.*

## **37.2 Healthy eating**

The hui discussions made clear that in conceptualising health campaigns and messages there is a need to move beyond the simplistic notion that Māori do not know they are sometimes making

poor food choices. They do. The challenge is how to make those changes. As one female participant said to nods of approval, “It’s up here. It’s a mental block for me.” Although there were some predictable jokes about rabbit food, participants could easily identify healthy foods and practices (fruits, vegetables, water etc.).

### **37.2.1 Food as an addiction**

Several participants likened food to an addiction.

*MWD: I think when it comes to diabetes what we eat is like an addiction too. You know we crave things like an addiction. You eat it or drink it all and then feel bad later just like an addiction.*

It prompted this response from a fellow participant.

*MWD: The thing is I’m probably one of the worst role models for teaching our own whānau about how to eat properly. The craving for sweet things is just so strong that I feel sick after having it.*

### **37.2.2 Role of Whaea (Mother)**

Both groups of women assumed responsibility for cooking for the whānau. Whereas the majority of the men’s discussions focused on physical activity, the women spent more time discussing food, probably reflecting their roles as mothers and meal providers. There was some discussion after a difference of opinion was expressed between one participant who suggested lifestyles have changed and another who insisted it was still the role of the mother to prepare home cooked meals.

*FWD1: I come from an era when we were all active and we did have big meals because we were active. But every whānau is busy now. With two parents working who actually has the time to sit and prepare? It’s just behavioural change and lifestyle.*

***Facilitator: And takeaways***

*FWD2: Isn’t that the mum’s job?*

*FWD1: I don’t even know if it is about takeaways. A lot of families eat takeaways. But it is about fast food. It could be about bacon and eggs!*

***You said it’s the mum’s job. What did you mean by that?***

*FWD2: I just feel that it's my job to cook properly for my children so they don't pick up the habits that I've got.*

*FWD1: That's a myth sorry!*

*FWD2: But even though I think that I have to do that it just depresses me that I have to do that.*

The theme of the mother's responsibility for healthy eating was also discussed in the other group.

*FND: I mean us as mums we are usually the ones who do the grocery shop and most of us are directed by our tamariki; they'll want the chips; they'll want the drinks... But because I was the one getting the groceries I would always point the finger at my daughter and say stop drinking that coke! And I forget to point the finger at me and say mummy stop buying the coke and the kai!*

### **38. Barriers: Traditional food gathering versus contemporary lifestyles**

Whereas the men were nostalgic for the outdoor experiences of their youth, women lamented how contemporary changes in lifestyle had a negative impact on diet.

*FND: We had no shops but our diet was alright because we grew our own veggies. You had your own meat and your own eggs and you didn't have cakes. Only what your mother cooked and we had the eels and then dried them. And life was good because you were away from the shops. The only time we had ice cream was when we had a concert or a picnic.*

To some participants, changes in food consumption were linked to a loss of cultural traditions.

*FND: It is habitual for us to turn on the TV at 6 o'clock and eat kai while watching TV. It's habitual for us to wake up in the morning and have bacon, eggs and toast you know. A huge cup of tea. It becomes habitual. What I want to become more habitual is kapa haka, is waiata. It's going down to a nice clean coast and looking for kai moana; looking for puha, looking for watercress, taking our people out.*

Some female participants' comments had a political and environmental perspective, particularly because some traditional ways of gathering food are no longer viable due to factors such as pollution.

*FWD: What do I need to know? I need to know that I can still eat my mātaitai. See we don't get mātaitai anymore. We can't just go to the beach and on the rocks and get because we don't know what's healthy and unhealthy on our beaches anymore. That's a big thing for us. So if I was back where I come from, I'd have the titi, I'd have the paua and I could eat quite healthily down there. But I'm an urban Māori now. I eat at the supermarkets. What I know about diabetes? No. It's about what I can eat and how I manage that.*

### **38.1 Cost**

All of the groups explicitly linked barriers to healthy eating to socioeconomic factors. While men were again nostalgic for the past, this did not stop them from acknowledging that socioeconomic factors have an impact on healthy diet.

*MND: We've talked about the issue of poverty and the fact it's economic. It's a fallacy. Unhealthy food is dirt cheap and healthy food is almost exorbitant to buy it. So they are not making it easy.*

Participants also linked socioeconomic backgrounds and multiple demands on time to a failure to consider personal health.

*MND: And I think it's true too most of us in this room probably come from a lower socio economic area in the country. And you know you get what you get back in the day (men laugh) hey you know! And that's a symptom of poverty if you like. Low education, poor diet, lack of information and the willingness. You know when all these factors are against you, you are not necessarily going to think about your health. Do you know what I mean? You are just living day to day...I mean I just look at myself and at the end of the day no matter how sophisticated I might think I am, I'm still kind of like a bogen from Papanui! I might have a nice TV but all that old stuff comes back man.*

### **38.2 Whānau resistance**

Another barrier discussed by the women's groups was a resistance to change by close family members.

*FWD: So I was diagnosed three years ago and we weren't really informed he kept on eating the same thing. I'd say, 'can't you die from eating something like that?' And he'd say, 'well you might lose a few limbs but you know!'*



One woman expressed her exasperation at her diabetic husband as follows:

*FND: He cooks all these things that diabetics should not eat in great quantities. He's just going to need to have a mind-set change because he just keeps continuing bringing things out that I know I shouldn't be eating that! I'm just thinking it's going to be an uphill battle...Yes it's learning all over again what he can cook and what he can't cook. We've talked about this but he doesn't listen though. He doesn't listen!*

Concerns for the next generation and the tamarki (children) were also expressed.

*FWD: I think it's one thing letting your kids know you have diabetes but it's whether the message is getting through to them. It's not getting to my kids. No! My boys say, 'well if we get it we get it Mum.' And I say, 'well yeah you're going to end up like me.'*

### **38.3 Advertising/Big food companies**

Whereas both groups of participants with diabetes did not believe the media plays an active role in influencing their food choices, both the FND and the MND groups expressed a strong belief that the media do have an influence.

The FND group generated some discussion about the need to counterbalance unhealthy food advertising with programmes promoting healthy food. A television segment, *Food in a Minute*, was praised but the clear sentiment from the group was that more educational programming is needed to counterbalance the marketing heft of large companies.

*FND 1: On the TV. Five thirty, six o'clock onwards. You switch on the TV there's food galore and it's always the bad food. KFC...*

*FND 2: Burger King and Pizza...*

*FND 3: You name it flashing across. And then you get the small little minute window of a healthy meal in a minute. It should be half an hour. Every hour before the news, not just a five minute slot.*

*FND: But it's those big companies that have the money to control ...Why should we have these big companies promoting crap?*

The MND discussion centred on the idea that advertising is misleading people into making unhealthy choices.

*MND: We are fighting a pretty big machine here. Why are we eating all this sugary stuff? Because someone makes lots of money off it. Someone at that top! We are fighting a big game here man. I agree we have to get tough on it. But it's pretty difficult.*

What was also notable in the discussions was that both groups addressed the role of mailers in influencing food choices.

*MND: It's not so much the TV media that doesn't affect me but when I see those flyers and pamphlets that say 10 percent off KFC or whatever, that affects me!*

*FND: You know how you get delivered pamphlets? That's another form of media because they are dropping them every day. I've got a pull out page with Pizza Hut and you know all the little coupons and specials that are going at the moment. I've got a pamphlet from McDonalds on all the combos you can buy; that you can get so many burgers, chips, drinks, sundaes for the low cost of twenty dollars. Obviously that is going to appeal. It's all provided and it's only going to cost twenty bucks.*

### **39. Diabetes service barriers**

Given the findings of the key informant interviews, and the emphasis placed on service delivery barriers, the facilitators of the groups with diabetic participants included a discussion on this topic. Participants with diabetes discussed some of the same service delivery barriers identified in the key informant interviews. They include distrust of health services, breakdowns in communication, culturally inappropriate treatment options, and a general dislike of dieticians.

Several participants emphasised the importance of receiving culturally appropriate medical support from Māori health workers.

*MWD: Too many times I've heard Pakeha say this is diabetes and this is how you are supposed to do things but it doesn't affect me as a Māori because they are not looking at it from a Māori perspective.*

Another man recalled this heated exchange.

*MWD: I know the nurses in there and they were lovely people but they weren't getting results because they weren't asking what the underlying issue was. They don't look at the underlying issues as to why we don't care. And they said, 'you won't get a Māori nurse you'll get a Pakeha one.' And I said, (laughing) 'did I say I want a fucking Pakeha nurse! I don't! Now if they aren't*

*here I'll come back next week'. And she goes, 'but there's no difference your doctor is white.' I said, 'do I look like I care? They are the ones I talk too. They are on my team, not you. There's that common courtesy.'*

One of the key informants had observed that “our people have that perception of mistrust before they come in,” a sentiment reflected by a male participant.

*MWD: But the other thing is too about the Māori understanding you know, this thing isn't in isolation because if you are Māori you come in the door you've got a big back pack on your back. It's not just diabetes that you are bringing.*

Poor communication with medical staff was also discussed. Several key informants had raised this point in their interviews with some critical of the medical jargon employed to explain diabetes. The same point was made by hui participants.

*FWD: I never ever get the same specialist. It's always a different one and it just goes straight over my head. I'm not dumb. I've been to university. But then they start throwing all these big medical words around and then I've got to go back and explain that to my kids and my mokopuna.*

*FWD: Those are strange words to our people. It's like glucose? I used to have glucose lollies when I was a kid so when you say the word glucose to me I associate it with the lolly you know? They use their terminology but it's not being interpreted down to basically an understanding of you eat this this and this. Or this is causing this, this, and this.*

Complaints about poor communication and inappropriate service delivery were particularly focused on the participants' interactions with dieticians.

*FWD: So I go to the dietician and automatically she brings all these big words up at me and then I just shut off.*

Again the need for a culturally appropriate medical support from a Māori health worker was emphasised.

*FWD: I want to know alternatives for Māori. Not a Pakeha view put on to Māori. I want to know that there's a Māori way of cooking kai. There's a difference in my thinking about how I do stuff in some things. So I just don't want that Pakeha dietician from the hospital, clinical person coming in saying you need to do this, this, this and this in a very nice way. I'd rather have the*

*Māori person saying to me if we need to do this then how are we going to get there and what do we need to change to get there?*

#### 40. Media resource

There was a brief concluding discussion at the end of the session about what participants would like to see in a digital resource. Those that expressed an opinion argued for real people over actors. Participants were most interested in hearing from and seeing someone that had a lived experience of diabetes. This reflected the feedback from the key informant interviews.

*FWD: I want to see whānau ...I want real people. I don't want actors. I want to know that it is not easy. I want to know that it's okay to fall off the wagon because that's reality for us.*

Participants agreed that they were less interested in clinical or medical explanations. One participant made a detailed argument for older people to be seen as leading by example.

*MWD: For the old people setting an example shows the babies that are coming up with it how to do their thing. Because if we don't see it then we don't know it...So our older people need to pull their weight that way and encourage the kōhungahunga. This is how we are going to do it, Kaupapa Māori style.*

**Table 2. Hui themes**

<b>Prevalence Impact and Awareness of Diabetes</b>	<b>Illustrative Quote</b>
Prevalence	<i>We just knew. The thing in our family was well you're going to get it one day. It's going to hit you. So it was an expectation that we just got it. I grew up thinking that.</i>
Whānau	<i>Most of my whānau have died from it. My grandmother lost a leg. Then my mother developed it. My grandfather had it and my father.</i>
Experience	<i>I hate it (injecting) but I still do it.</i>
Fear	<i>When it shuts you down it shuts you right down. I'm forty nine. I haven't had sex for two years.</i>
Grief	<i>And I'm still in denial because I'm going to reverse it! And I'm truly informed so it's not like I don't know the story.</i>
Denial	<i>I thought oh well I'll stop taking sugar and that will cure me. Well I got a rude awakening.</i>
Misconceptions	
<b>Barriers to Physical Activity</b>	
Financial	<i>There is no funding. They used to have it where they would assist you in going to a gym so you could do a workout. It's just not here.</i>

Stress	<i>It depends on what kind of a day I'm having. Otherwise out comes the remote!</i>
Low Motivation	<i>My brain wants to play but my body doesn't. I wake up every morning and there's an exercycle looking at me and I push it up against the wall.</i>
Low Self esteem	<i>I went down to the other one (gym) once on the other side of town and it was packed so I just wouldn't go back. I didn't feel comfortable over there.</i>
Earthquake	<i>It's too scary to go out there sometimes.</i>
<b>Barriers to Healthy Eating</b>	
Food as addiction	<i>You know we crave things like an addiction. You eat it or drink it all and then feel bad later just like an addiction.</i>
Mother's choices	<i>I forget to point the finger at me and say mummy stop buying the coke and the kai!</i>
Time	<i>With two parents working who actually has the time to sit and prepare? It's just behavioural change and lifestyle.</i>
Lost traditions	<i>We had no shops but our diet was alright because we grew our own veggies. You had your own meat and your own eggs and you didn't have cakes. Only what your mother cooked.</i>
Environment/ Pollution	<i>See we don't get mātaitai anymore. We can't just go to the beach and on the rocks and get because we don't know what's healthy and unhealthy on our beaches anymore.</i>
Cost of healthy food	<i>It's a fallacy; unhealthy food is dirt cheap and healthy food is almost exorbitant to buy it. So they are not making it easy.</i>
Whanau resistance	<i>He's just going to need to have a mind-set change because he just keeps continuing bringing things out that I know I shouldn't be eating.</i>
Advertising	<i>We are fighting a pretty big machine here. Why are we eating all this sugary stuff? Because someone makes lots of money off it.</i>
<b>Diabetes Care and Service Delivery</b>	
Distrust	<i>If you are Maori you come in the door you've got a big back pack on your back. It's not just diabetes that you are bringing.</i>
Poor communication	<i>So I go to the dietician and automatically she brings all these big words up at me and then I just shut off.</i>
Cultural insensitivity	<i>I want to know alternatives for Maori. Not a Pakeha view put on to Maori.</i>
<b>Goals for Health Promotion Resource</b>	
Real people	<i>I want to see whanau...I want real people.</i>
Easy to identify with	<i>I want to know that its' not easy. I want to know that it's okay to fall off the wagon because that's reality for us.</i>
Positive role models	<i>For the old people setting an example shows the babies that are coming up with it how to do their thing.</i>

## **41. Discussion**

The hui encouraged a frank and open discussion between the participants. Because the groups were divided by gender, and led by Māori community members, participants felt more comfortable talking directly about their experiences. At least three participants verbally confirmed this observation on the day to both me and to members of the Community Advisory Board. In addition, having experienced educators leading the groups created the opportunity for education about type 2 diabetes. This two way exchange of knowledge is a good example of CBPR principles in practice.

The discussions confirmed many of the themes identified from the key informant interviews. Type 2 diabetes is prevalent in the community and most participants had direct experience with at least one close family member with the disease. However, this did not translate into knowledge about the causes and symptoms or ways to prevent type 2 diabetes. The hui data confirmed that a common misconception about type 2 diabetes is that it is caused by consuming too much sugar. As the key informant interviews had previously indicated, there was a sense of fatalism about the disease with many Māori participants considering an eventual diagnosis inevitable. There was also a lot of fear, denial and grief surrounding the disease. Significantly, the strongest motivator for participants maintaining or working towards good health was being there for the mokopuna (grandchildren). But barriers to good health were considerable and include time, cost, family pressure, cultural norms, advertising and service delivery barriers. Some participants talked of food as an addiction. This underlined how difficult some behaviour can be to change. Also the fact that so many of the participants were sedentary was identified by the CAB as a significant challenge for improving health and preventing type 2 diabetes.

### **41.1 Implications for documentary messaging**

A number of potential key messages were identified at this stage. As with the previous stage of research, the CAB felt strongly that we needed to address the misconception that diabetes is a death sentence rather than a disease that can be prevented and managed. The misconception about sugar as a cause should also be addressed. Another key message would address motivation for change. It was clear from the interviews that the primary motivation for good health was being there for the grandchildren. We also agreed that the service delivery barriers discussion would have a bearing on who should feature in the documentary. It would be important to feature

Māori health workers. We would also need to counter the perception that health messaging is too negatively geared. It was felt that featuring “cheerleaders” from the community might help counter the pervasive sense of grief and fatalism about the disease that appeared to be so common in the community. We then discussed the identified barriers to healthy eating and movement and exercise. It was agreed that messages about eating should be sensitive to cost. Given the sedentary behaviour of many of our hui participants, we also agreed that key informant advice to take small incremental steps to change would be an important and realistic message.

In the next chapter I will describe how this research data was translated into a documentary narrative and resource. The selection of an appropriate behavioural theory is described. Discussions with the CAB about what we wanted the audience to know, think and believe are outlined. The importance of an additional hui to refine the messaging is explained. The remainder of the chapter will focus on the creation of the documentary and the application of social cognitive theory to shape the messaging.

## **Chapter VII. Documentary Production**

### **Chapter Overview**

The aim of this chapter is to explain how the major findings from the key informant interviews and hui discussions informed the content and messaging of the documentary resource. I explain why social cognitive theory was an appropriate framework for the documentary. I pay particular attention to Bandura's theory about enhancing collective social cognitive factors and provide illustrative examples from the documentary. I then detail how the specific knowledge, attitude and behaviour change goals were formalised with community input and describe the results of an additional hui held to refine the approach. Relevant examples are given and the reader is directed to the full script and an online link to the completed resource.

#### **42. Why social cognitive theory was selected**

One of the major research gaps identified in the literature review is the failure of previous diabetes initiatives to employ behavioural theory in the shaping of messaging for Māori audiences. In their report on the Lets Beat Diabetes campaign, McNeill et al. (2008) found that the theories supporting the campaign were not clear to the key stakeholders. Further, the Ngati and Healthy campaign did not employ behavioural theory in messaging. Similarly, none of the previously produced videos discussed the use of behavioural theory in the shaping of messages or content.

As previously described in the literature review, an expert panel convened by the Centers for Disease Control and Prevention concluded that health interventions targeting a specific racial or ethnic minority group should pay particular attention to theory selection because some theories can be a poor fit with the realities of vulnerable populations (Kennedy & Abbatangelo, 2004). Randolph and Viswanath (2004) argued that one of the most critical conditions for a successful communication intervention is an understanding of the determinants of behaviour in order to influence the behaviour. Yet in a review of articles published between 1998 and 2003 they found less than one third reported the use of a theory that informed the message production or intervention strategy. Likewise, they did not find many health interventions framing messages in culturally appropriate ways when targeting specific racial or ethnic minority populations.

As will be detailed below, Bandura's social cognitive theory was a perfect fit to address the problems identified by my research. As the key informant and hui results have shown diabetes prevention is a complex and multifaceted problem in the Māori community. First, there is a clear



lack of knowledge and understanding about the causes of type 2 diabetes. At the same time it is common to have witnessed family members poorly manage complications from the disease or die from it. Not surprisingly this has resulted in a strong sense of fatalism and the belief that diabetes is a death sentence. Second, there are multiple barriers for Māori in improving health and preventing the disease. They are economic, social, cultural and institutional. As a result, depression, stress, low self-esteem and low motivation impede health behaviour change. However, the key informant and hui research also identified viable solutions. These included a holistic model of care, collectivist whānau based approaches, taking small and achievable steps to good health, and promoting the achievements of positive role models from the community. Therefore the data suggested that the first step in encouraging behaviour change would be increasing knowledge about type 2 diabetes risk factors. It would then be necessary to increase collective efficacy with positive health messaging to counter the low self-esteem and low motivation prevalent in the target audience.

Social cognitive theory has a long and established use in health communication initiatives and Bandura's theory is particularly helpful for increasing the personal and collective confidence necessary to influence beliefs and behaviours. Bandura's (1986) observational learning process provides a model to structure communications messages for knowledge, skills development and confidence building all of which can be demonstrated through documentary video. There were two other reasons why social cognitive theory was selected. Bandura (1997) recognised that people do not live in social isolation and that the strength of a community is often rooted in a sense of collective efficacy as a means to overcome shared problems. Bandura (1982) argued that the strength of a group is based in part on people's belief that collectively they have the ability to solve their problems and improve their lives. This is an important distinction as Māori cultural identity is collectivist. Unlike other behavioural theories that are very individualistically focused, social cognitive theory allows for messaging that enhances collective social cognitive factors. Social cognitive theory was also appropriate because it allowed me to frame the community based research recommendations and shape the documentary messages in a way remained culturally sensitive. Bandura's emphasis on efficacy maintains an emphasis on positive messaging and consequently avoids blaming or pathologising Māori for poor health outcomes. As has been previously argued, the communications focus of research with indigenous communities needs to be reversed from a deficit model of health to one that places primacy on communicating positive stories from the community (Pyett et al., 2008).

### 43. Application of social cognitive theory

Bandura's (1986) concept of reciprocal determinism explained that an individual's behaviour both influences and is influenced by personal factors and the social and physical environment. Accordingly, interventions that enhance social cognitive factors (expectations, beliefs and goals) can improve the rate at which associated health behaviours are adopted. The first step required for any behaviour change is knowledge about risk factors. Our formative research confirmed that not only was knowledge about type 2 diabetes low, there were a number of misconceptions about cause, and a fatalistic attitude that it was an inevitable death sentence. We used this as an opportunity to introduce well respected Māori health workers into the documentary narrative to provide information that countered misconceptions and a Māori doctor to explain diabetes in conversational non-medical language.

As Maibach and Cotton (1995) observed, while one of the strengths of the communication process is the transfer of knowledge, knowledge alone is not sufficient to motivate behaviour change. People also need the necessary skills. Bandura's (1986) observational learning process again provides a model to structure communications messages for skills development. Our formative research showed that Māori wanted to see local role models and culturally relevant solutions. Subsequently, the documentary featured a number of skills building messages and demonstrations of successful behaviour from local Māori who had made lifestyle changes. This included culturally relevant food preparation and exercise. The documentary featured a local man who derived physical benefits from regular kapa haka (Māori performing arts), a Kaumatua (elder) preparing healthy food, and the main characters (a young family) preparing a traditional Māori boil up in a more nutritious way.

Bandura (1986) believed how people think and behave is determined by their confidence in their ability to organise and execute a successful course of action. Health behaviour is influenced by personal self-efficacy as people typically avoid attempting change they feel they cannot achieve. Maibach and Cotton (1995) argued that like knowledge and skills, self-efficacy can also be influenced by the communication process. For example:

**Performance Mastery:** Bandura stated that successfully performing a task increases a sense of efficacy. Maibach and Cotton (1995) agreed that health messages should encourage people to try a new behaviour in an achievable way and in an environment most likely to contribute to success. The documentary featured several examples of this in practice. The featured family were supported by a community health worker. Together they created a food plan, tried some

simple recipes, and introduced some basic lifestyle changes like walking to the grocery store and getting up and moving during commercial breaks on the television. Once again the goals were informed by the formative research themes that goals should be achievable (small changes and moderation) and that messages should be positive and not negatively focused.

**Vicarious Efficacy Information:** Bandura (1986) explained that seeing people succeed who are behaviourally and demographically similar increases the observer's belief that they can successfully master a task. The family selected for the documentary faced many of the barriers to healthy living identified in the hui, the two biggest being time and money. Subsequently key scenes focused on ways the family could create quick healthy meal options and introduce movement into their busy days. One key scene featured Jodi's (Mother) discovery that cooking burgers at home was half the cost of takeaways. All of the featured role models and local health workers were from the community and demographically similar to the target audience.

**Persuasive Efficacy Information:** According to Bandura (1986), positive verbal encouragement from others helps people to overcome doubt and persuades them that they have the necessary skills to succeed. Maibach and Cotton (1995) recommended health messages focus on people's strengths. This fit well with the formative research that demonstrated a clear preference for positive health messages and humour. The documentary featured one of our role models listing all the potential excuses he could come up with not to change. Each excuse was met with a positive rebuttal and helpful advice from documentary participants.

**Personal Goals:** Bandura (1986) notes that one of the major sources of motivation for behaviour change is the setting of personal goals. In the documentary the family set a number of short term goals. These included replacing carbonated drinks with water, reducing takeaway food consumption and introducing more movement into daily routines. Maibach and Cotton (1995) recommended the creation of health messages that establish positive outcome expectancies. As they noted, Bandura made a distinction between beliefs about one's ability to perform a behaviour and beliefs about what the outcome of the behaviour will be. Bandura (1986) said people will be more motivated to attempt a behaviour change if they also believe it will produce favourable outcomes. The documentary contains a number of positive messages that highlight the physical effects of modifying food choices and increasing physical movement. However, the most important message is the focus on making change for the good of the family. Our formative research showed that messages focused solely on personal change had less resonance with a collective culture like Māori. The key message of the documentary was that change is a collective responsibility and that it's important to be there for the moko (children) and mokopuna

(grandchildren). As one role model states, “We’ve got mokopuna that we need to look after. Without us who is going to guide them?” The importance of being there for the grandchildren is also reflected in the title of the documentary itself.

Now that I have established why social cognitive theory was an appropriate framework and have provided some examples of key scenes, I will describe the role of the community in shaping the documentary messaging. Together we articulated knowledge, beliefs and behavioural objectives that informed the documentary narrative and filming. This was important because in doing so I maintained the commitment to community participation while maintaining a theoretical framework and application of behavioural theory messaging absent from previous health communication initiatives with Māori.

### **43.1 Approach to documentary messaging**

The CAB met for a pre-production hui to determine the approach to and content of the documentary. We reviewed the key themes tables from the key informant interviews and hui, as well as the hui summary tables (see Appendix H). We then discussed three key questions:

- 1) What did we want our audience to *know* about type 2 diabetes? [Knowledge]
- 2) What did we want our audience to *believe* about type 2 diabetes? [Collective efficacy and ways to increase positive outcome expectancies]
- 3) What did we want our audience to *do* to prevent/decrease likelihood of getting the disease? [Behaviour change]

As a group we summarised the answers as follows:

### **43.2 What do we want our audience to know about type 2 diabetes?**

Bandura (1986) stated that the first step required for any behaviour change is knowledge about risk factors. Given the low level of community knowledge, it was agreed that we needed to raise awareness and understanding of type 2 diabetes and its associated risk factors. Therefore the documentary should convey

- Type 2 diabetes is a significant health issue for Māori but it can be prevented/managed
- Cause: This should be a simple explanation free of medical terminology. It should also address the misconception that it is caused by consuming too much sugar
- Risk factors. These should be clearly and simply identified. For example, type 2 diabetes is sometimes referred to as a lifestyle disease (due to the lifestyle we have, how and what

we eat and how much exercise we get). Risk factors: A family member with the disease, food choices and lack of exercise. A major cause is being over the healthy weight range

### **43.3 What did we want our audience to believe about type 2 diabetes?**

The key message the CAB prioritised was addressing the misconception that diabetes is a death sentence. We wanted to counter the perceived sense of fatalism about the disease with a positive message about prevention with the aim of increasing self-efficacy. And Bandura (1986) said people will be more motivated to attempt a behaviour change if they also believe it will produce favourable outcome. Therefore the messaging suggested the overall goal should be to make changes for the children. At the same time, the CAB advised that messaging should be clear and simple and realistic. We should convey

- Diabetes is not a death sentence. It can be prevented with some basic modifications to food choices/exercise (There are local role models showing us the way)
- Māori health is holistic. It is important to make changes for the whānau. Diabetes is a community responsibility. Let's do it for our tamariki (children) and our mokopuna (grandchildren)
- There are many simple things that you and the family can do to prevent type 2 diabetes. Moderation is key (performance mastery and personal goals)
- Small changes are manageable changes. It will not be expensive or take up too much time
- There is community support. Local community health workers are there to help

### **43.4 What did we want our audience to do to prevent/decrease likelihood of getting the disease?**

By focusing on the prevention of type 2 diabetes it was hoped that this educational tool might contribute in the long term to an overall reduction in morbidity and mortality in the target population. We identified two primary objectives.

Our nutritional objective was to reduce the amount of fat consumed every day. The qualitative research findings suggested that takeaway food consumption was high which is also borne out in statistical studies. A national study on Māori nutrition found that Māori females were three times more likely to consume fast food or takeaways three or more times a week (*A Focus on Maori Nutrition: Findings from the 2008/09 New Zealand Adult Nutrition Survey*, 2012). Further, a detailed review of the national Healthy Eating-Healthy Action (HEHA) strategy noted that very

few initiatives focused on decreasing high fat foods or sedentary behaviour (McLean et al., 2009). Most important, as we wanted to focus on simple changes, a focus on fat reduction allowed us to introduce the idea of simple healthy swaps to daily food choices. This was previously found to be an effective messaging strategy with the Let's Beat Diabetes campaign (McNeill et al., 2008).

Our physical activity objective was simply to get people moving on a daily basis. While Ministry of Health recommendations are for thirty minutes of moderate intensity physical activity at least five days a week (How much activity is recommended? 2015), CAB members considered this to be an unrealistic goal given that hui participants reported participating in little if any physical activity. Key informants had advised that they recommend small and incremental steps to their clients. We also decided to focus on incremental changes such as taking the stairs instead of the elevator. Our goal was to get sedentary people to participate in any activity that made them “huff and puff” each day and encourage them to believe that keeping active can be fun and free.

The CAB felt both objectives were realistic and achievable goals. Both objectives were selected to neutralise two key barriers to change identified in the hui analysis - time and money. Consistent with the indigenist principles underlying the research approach, the communications focus would be reversed from a deficit model of Māori health to a focus on positive messages highlighting community strengths and resilience. The focus on whānau was culturally appropriate and most important, was positioned as the key reward for implementing health changes. The personal gain would be being present and healthy for the children and grandchildren. This definition of good health was a dominant theme from the hui discussions. Further, this was a strategy with a previously documented record of success (Grigg et al., 2008).

#### **44. Refining the approach: Women's hui**

It was evident from the hui discussions that women continue to make the majority of food purchases for the whānau and that despite economic, cultural and environmental barriers, many of them were concerned about food choices and physical activity levels for the family. Before recruitment for participants to feature in the documentary began, I met informally with a group of six Māori women recruited by a member of the CAB. We met at the offices of Whānau Tautoka, the location used for the hui. The women were between the ages of 18 and 40 and all had at least one child at home. The goal of the discussion was to determine what small changes to fat reduction and physical activity they deemed to be most realistic and achievable. Given the conversational nature of the meeting, the women indicated that they would prefer that I take

notes and actively participate rather than audio record the conversation. At the end of the meeting I reviewed my notes and summarised the key points made by participants and asked them to verbally confirm that my summary accurately reflected their observations. After securing their confirmation, immediately after the meeting I wrote up my notes in the form of a reflective memo.

#### **44.1 Approach to nutrition**

The first part of the discussion was based around determining the best way to reduce fat intake. I used a handout “How to Keep Your Fat Intake Low,” that I had been given by a community health worker. The handout lists ten ways this can be done.

The group identified trimming visible fat from meat, removing fat from the top of casseroles, and baking rather than frying as changes they thought they could easily make. This could have significant health benefits as four of the women said they eat meat at least three times a week and two of the women said they eat meat every day. There is an example of this in the documentary when the fat is removed in the preparation of a healthy “boil-up.”

The group felt that the recommendation to limit takeaways to once a month was unrealistic but they were willing to choose takeaways that were not deep fried. I asked them if they would be interested in cooking healthy fast food alternatives at home and there was unanimous agreement they would but that education and demonstration were key. This feedback was incorporated in to a scene in the documentary. Given the high rates of takeaway consumption key informants had previously discussed how they educated their clients about fast food. As one nurse had commented

*For what it costs to take four children and two adults to McDonald's that's half your groceries for the week if you were eating basic foods...And this is the message we are trying to get to our people. Keep it simple. You don't need to go to MacDonal'd's to have a burger. You can get some meat and make your own burgers.*

As a result we created a scene in the documentary where a community health worker helped the family to make homemade burgers and oven baked fries. This addressed the women’s request for demonstration and provided an opportunity to visually and verbally reinforce a cheaper and healthier alternative to fast food.

Notably, while two of the suggestions on the handout were to add dried beans and lentils to dishes, none of the women knew how to cook with them. One participant commented that she wanted to know how to cook healthy food but also needed the tools to make the change.

*“We don’t know what to eat. We need ideas and choices. We need alternatives to takeaways when you are starving, have been at work all day and just need something quick.”* We also discussed implementing simple food swaps. Switching to lower fat milk was identified as the best swap to make. As one woman commented, *“You have to get a taste for it. Or rather lose your taste!”* But all of the women indicated they would be prepared to try lower fat milk. Other achievable food swaps discussed included swapping to lighter versions of mayonnaise, cream cheese and coconut milk. Again examples of this can be seen in the documentary. The family are shown switching to lower fat milk, butter and mayonnaise. And the food that the family learn to prepare is both quick to make and affordable.

#### **44.2 Approaches to movement**

We then discussed the second handout, ‘Tips and Ideas for Adding Movement to Your Life.’ The women responded favourably to all of the suggestions as they were seen as both realistic and achievable. Two of the participants cautioned that they would rather be told to try and be active every day rather than having a goal or specific number of minutes of physical activity to achieve. The women particularly liked the idea of walking the children to school, being active during television advertisements and getting friends together for a walk. One of the participants suggested that it be named a “gossip walk” as a way of increasing participation. And as another participant pointed out, *“you won’t think about exercise if you are too busy talking!”* Examples of all of these ideas were incorporated into the documentary. Jodi (the featured mother) walks her children to the store, vacuums and dances during the commercial break with her baby. And the female “cheerleader” is filmed walking her dog with friends.

#### **44.3 Potential approaches to content**

The final part of the discussion focused on potential approaches to the documentary content. I provided an overview of current research findings and described a potential approach to filming. Given the need for the documentary to be whānau based I described a potential story line following a local family for a few weeks as they attempt to implement some of the changes (reducing fat/increasing movement). The emphasis would be on skills building and self-efficacy.



The women liked the approach and several added that it was important that the story be positive, include children, and avoid “don’t messages.”

Notably from this discussion came the eventual title of the documentary. Like the hui participants, all of the women emphasised the importance of making changes for the children and grandchildren, and one suggested the title, “I want to walk with my moko.” One key change to the documentary content came as a direct result of this discussion. I had originally intended to weave the stories of female role models throughout the narrative. While the women liked the idea of positive role models they all said they wanted to see male role models included. Their stated frustrations again mirrored comments from women in the key informant interviews and hui who were exasperated that their men refused to listen to their concerns about their health and believed themselves bullet proof. The women thought that stories of positive male models would be one way to get their partners to watch the documentary. As a result the documentary features a younger male and a Kaumatua with diabetes telling their story and reflecting on lessons learned. After the women’s hui was completed I summarised the key themes from the research data, the implications for social cognitive strategies and potential messages for the documentary. See Table 3 below.

**Table 3. Documentary Message Design**

<b>Key Informant Interviews</b> Purposeful sampling (Patton 2002) Snowball strategy (11 interviews) Semi-structured interview guide		
<b>Key Themes</b>	<b>Implications for Social Cognitive Strategies</b>	<b>Potential message for Documentary</b>
Māori perceive diabetes as a death sentence. Fatalistic	Knowledge: Perception of the environment: A misperception to be corrected	Diabetes can be prevented, controlled & managed
Misconception about cause: Most patients believe it is caused by consuming too much sugar	Knowledge: A misperception to be corrected	Diabetes links to lifestyle. Food choices, exercise, weight
Service delivery inadequate & often culturally inappropriate. Institutional racism remains. Diabetes education is too technical/confusing/negative	Persuasive Efficacy: Emphasise role of community health workers and non-clinical language/setting. Use storytelling and local cheerleaders to encourage performance mastery and collective efficacy	There are a few simple changes everyone can make. Local whānau workers are there to support you
Barriers to healthy living for many Māori  1. Environmental  Cultural: Māori belief re food that “big is good.”  2. Cognitive  Lack of self esteem	Opportunity for observational learning. Identify community role models who have had similar experiences  Personal goal setting  Persuasive Efficacy: From community health workers/role models	Moderation is key. Make small achievable changes. E.g. healthy boil-ups by trimming fat from meat

<p style="text-align: center;"><b>Hui</b></p> <p style="text-align: center;">Interview guide developed with Key Informant and CAB input</p> <p style="text-align: center;">Hui led by CAB members</p>		
<b>Key Themes</b>	<b>Implications for Social Learning Strategies</b>	<b>Potential Message for Documentary</b>
<p><b>Barriers Behavioural:</b> Lack appropriate knowledge to change food behaviours</p> <p>Belief health messages too negative and unrealistic</p>	<p>Performance Mastery: Demonstrate practical skills &amp; benefits</p> <p>Persuasive Efficacy: From community health workers &amp; local role models</p>	<p>Do it for the whānau/mokopuna (family/grandchildren)</p> <p>There are a few simple changes everyone can make</p>
<p>Being healthy is holistic. It's about whānau</p>	<p>Persuasive Efficacy: From community health workers</p> <p>Vicarious Efficacy: Local role models.</p> <p>Personal goal to support whānau</p>	<p>Health is not just physical. It's about being there for the whānau</p>
<p><b>Barriers Environmental</b></p> <p>Cost: Fast food is cheaper</p> <p>Cultural: Māori belief re food that "big is good."</p> <p>Traditional food gathering no longer practiced/pollution</p> <p>Hard to convince whānau to change</p>	<p>Collective Efficacy: Centre story around a whānau setting small goals and making moderate changes</p> <p>Acknowledge barriers and emphasise incremental steps</p>	<p>Being healthy doesn't have to be expensive or take more time.</p>
<p><b>Barriers Cognitive</b></p> <p>Lack of self esteem</p>	<p>Persuasive Efficacy: From community health workers/role models</p> <p>Performance Mastery: Demonstrate practical skills and emphasise benefits: Whānau and role models</p>	<p>Positive messages. E.g. have a plan. Small steps. Exercise can be taking the stairs instead of the lift.</p>

#### **44.4 Treatment: Whānau leading whānau**

I then translated these findings into a documentary treatment and script outline. A treatment outlines a visual approach and the potential storyline and key health messages. Given the nature of the documentary format it is impossible to script at this stage and predict exact lines. However, it is possible to outline and describe scenes, characters, likely scenarios and voice over. The approach to the documentary was to follow a young family attempting to make some positive health changes, include some local role models who might serve to inspire the audience, and weave in some positive messages and encouragement from local Māori health providers. It was important to focus on a family and emphasise a collective as opposed to individual effort. As a previous discussion of the “it’s about whānau” smoking campaign showed, a whānau focus is culturally appropriate and encompasses one of the four elements of the Te Whare Tapa Wha Māori health model (Durie, 1998). As the designers of the campaign explained, whānau plays a dualistic role. Not only does it suggest a supportive environment, it also conveys a shared obligation on the part of each person to change to support their whānau members (Grigg et al., 2008). Similarly, Blundell et al. (2010) cite Jones, Crengle, & McCreanor (2006) to argue that whānau leading whānau promotes Mana Whaahaere (independence) and accountability.

#### **45. Digital resource creation: Production**

The CAB then utilised their networks and helped to recruit participants. At the same time funding was secured from local PHOs, Ngāi Tahu and the Maurice and Phyllis Paykel Trust to cover the associated production costs. Sir Mark Solomon’s Kaiwhakahaere (Chair) Ngāi Tahu willingness to be interviewed for the documentary ensured mana (prestige) for the project and recruitment was completed within six weeks. The majority of the filming occurred over a two week period. The crew consisted of me directing interviews and my partner operating the camera and running audio. The whānau that participated were recruited through a local Māori Health Provider who also volunteered one of their community health workers to support the whānau. I met with her prior to filming commencing to review the treatment and key messages to convey. We also discussed ways we might film that would encourage visual and verbal examples of the application of social cognitive factors. She then came up with a strategy that met the criteria that the encouraged changes be realistic, achievable and culturally appropriate. I agreed to follow her lead and to record the action as it happened. There was to be no prior scripting or delivered narration. Before filming commenced I also met with the family to explain how we would film. I

let them know that they could request at any time that I not use any footage or interview soundbites that they were uncomfortable with. I also informed them that they would see the first cuts of the edited documentary (offline) and again would be able to flag any parts they would not like used.

Role models were recruited by members of the CAB and included one CAB member who had made some major health improvements following an initial diagnosis of type 2 diabetes. A formal interview was conducted with each of the role models that explored how and why they had made changes and what positive outcomes they had experienced. Supporting footage was shot that showed each role model implementing the healthy behaviour (for example, basic food preparation). Again, I focused on visual and verbal examples of the application of social cognitive factors. One of the role models, a radio DJ also incorporated a “What’s your excuse?” section where he listed top reasons given in the hui for not eating healthy food or being active. His excuses were met by counterarguments from other documentary participants. This injected some humour into a serious topic matter.

A male and female “cheerleader” male and female were also recruited from the local District Health Board and Primary Health Organisations. One of the CAB members who had been involved with the research from its inception served as the male cheerleader. The cheerleader role was to provide encouragement and support and address barriers preventing people from making positive health changes. They were interviewed to provide knowledge about risk factors, encourage performance mastery, and provide positive verbal encouragement (persuatory efficacy) and the setting of personal goals.

Another member of the CAB and a well-respected Māori doctor also delivered important knowledge messages. This was the only section of the script that was narrated. The rationale was that given the documented levels of confusion over cause, and lack of knowledge about the potential health consequences, a simple message from an authoritative source was required. I reviewed several potential explanations with the doctor and we selected a simple explanation posted on the Lets Beat Diabetes website. Sir Mark Solomon and Peter Mason (Nga Hau E Wha National Marae) were both interviewed for the documentary and recorded an introductory whaikōrero (formal introduction). Their seniority and mana were significant and conveyed prestige and support for the documentary.

#### **46. Community feedback**

After the first offline edit was assembled I took the film back to all of the participants for feedback and potential changes. No changes were requested. The documentary was then screened for members of the CAB and a group of six community members (three men and three women) invited by CAB members. After the film had been viewed in its entirety individual chapters of the film were reviewed. I wanted to determine whether the messages were clearly comprehended and perceived as culturally appropriate. I also asked about music choices. The group liked the simple explanation of type 2 diabetes and felt that the messages were clear and achievable. No scripting requests or shot changes were requested. I then provided screening copies to members of local PHOs who supported the creation of the film for feedback. No changes were requested. I then provided scripts and screening copies to my supervisors. A few minor changes were requested that strengthened the documentary's messages without changing the visuals. For example, I removed a couple of references to diabetes "management" in order to strengthen the key focus around prevention. The documentary was also screened for two University of Canterbury tutorial sessions (HLT 106- Nga Take, Te Wero - Māori Health Issues and Opportunities), with a total of twenty six students providing feedback. Viewers liked the positive perspective, use of real life people, positive role models, and felt that the messaging was practical and achievable. Because I did not attend the screening I could not ascertain how many of the students were of the same target demographic.

To view documentary go to <https://vimeo.com/128753884>

**See Appendix I for full script. The script highlights how key messages identified in the key informant and hui stage were incorporated into the final script. I have also noted the application of social cognitive theory.**

#### **47. Distribution**

The documentary was officially launched at an event hosted by Pegasus Health. Introductory remarks were given by Lisa Tumahai, Deputy Kaiwhakahaere (Chair) Ngai Tahu. He Oranga Pounamu (a Ngāi Tahu mandated organisation representing Māori Health Providers) and Pegasus HAdditional screenings took place at the National Diabetes Nurses Symposium in Christchurch and at meetings of the Māori Women's Welfare League. Channel North, a North Island television station also screened the documentary. The documentary was also housed on the Canterbury Clinical Network website, Health Info website (affiliated with the CDHB), and

the Māori tube website. Copies were also requested and acquired by organisations outside the Canterbury region. These included Southern DHB, Northland DHB, the Public Health unit at Taranaki hospital, Māori health lecturers at Dunedin School of Medicine and from Work Base: The New Zealand Centre for Workforce Literacy Development.

This chapter has demonstrated how the major findings from the key informant interviews and hui discussions informed the content and messaging of the documentary resource. I detailed how the knowledge, attitude and behaviour change goals were formalised and how social cognitive theory was applied. This process was unique in that it was the first time in New Zealand that an academic study utilised qualitative research data, community input and behavioural theory to create a culturally appropriate documentary resource for Christchurch Maori at risk for type 2 diabetes.

In the following chapter I will detail the process evaluation I conducted at the completion of the research. I applied Walters et al.'s (2009) eight indigenist principles throughout the CBPR process. Using pertinent examples drawn from the research I will build an argument that I successfully engaged Māori health leaders and community members in a participatory process. In doing so I will demonstrate that employing a CBPR approach helps reflect the cultural values, behavioural preferences, and environmental context of the participating community and that Walters et al.'s principles are a suitable process for evaluating the success of projects with indigenous communities.

## **Chapter VIII. Evaluation**

### **Chapter Overview**

In this chapter I will demonstrate why a process evaluation was an integral part of this study. I first offer a brief recap of the study's purpose, why CBPR was employed, and some of the identified research gaps I hoped to address. I then go on to demonstrate through a discussion of Walters et al.'s (2012) eight indigenist principles, how my research engaged the community in the co-production of a culturally appropriate diabetes prevention documentary. I will argue these principles serve as a good benchmark by which to assess the cultural appropriateness of research with indigenous communities.

#### **48. Process evaluation: Purpose**

The purpose of this study was to engage Māori health leaders and community members in a participatory process to develop a culturally relevant diabetes prevention documentary. In my literature review I built an argument that there is a clear and identified need for innovative approaches to diabetes education and prevention that reflect Māori cultural practices in ways that are appropriate for use in Māori communities. For example, I noted that few studies have focused on the perception and lay understanding of diabetes in indigenous populations or the social and cultural meanings of the disease (Boston 1997). I built on this evidence to argue that effective communication interventions are needed to address the disconnection between medical professionals' biomedical perspective on the disease and the cultural and experience based beliefs that influence how Māori experience and understand diabetes. I further argued that there is a need for health promotion materials that recognise and engage with the social context that effects racial and ethnic inequalities in health (Nazroo & Williams, 2003). This would include a consideration of historical, social and environmental barriers.

I made an argument for employing a CBPR approach to address this research gap and cited relevant literature that intervention strategies designed following its principles will reflect the cultural values, behavioural preferences, and environmental context of the participating community (Kieffer et al., 2004). More specifically I adopted Walters et al.'s (2009) eight indigenist principles to increase the chances of creating a culturally appropriate documentary.

I also stated that the process of working with a community needs to be made transparent and be documented. There is a gap in the literature when it comes to understanding the process of developing relationships and consulting with the Māori community. As discussed in the literature



review, while Ngati and Healthy's participatory community development model and Simmons et al.'s community development model appear to share similarities with CBPR, none of the published research documents the process employed in consulting with the community. Given that partnership development and collaboration is central to participatory research models, there is a need for research that makes explicit the processes of engaging community members. For these reasons evaluating the process was integral to assessing both the cultural appropriateness of the documentary resource and how well the indigenist principles were applied in the process of effective community engagement.

Second, in my methodology chapter I noted that there is continued debate about what constitutes good research and evaluation in CBPR projects. In order to evaluate the success of my study, I identified four appropriate evaluation criteria that would be applied. They were developed by Holkup et al. who adapted Guba and Lincoln's (1989) work to more appropriately reflect the CBPR process. The rationale for the selection of these criteria was fully outlined in the methodology chapter (19.2.2.).

I will begin the evaluation with an assessment of the first criteria used to determine methodological rigour. They are credibility, transferability, dependability/confirmability (Guba & Lincoln, 1989). Criteria two-four (see below) are focused on the CBPR process and will be incorporated into the evaluation of the eight indigenist principles also documented in Table 4. Holkup et al.'s criteria are useful for assessing methodological rigor and the community engagement process. Walters et al.'s (2009) principles are appropriate as they specifically relate to working with indigenous communities.

#### **48.1 Four evaluation criteria for CBPR: Modified by Holkup et al. (2004)**

- 1) Credibility, transferability and dependability/confirmability: *Used to determine methodological rigour* (Guba & Lincoln, 1989).
- 2) Level of community involvement (incorporates the principles of catalytic and tactical authenticity): *Used to determine level of community involvement throughout research process* (Guba & Lincoln, 1989).
- 3) Acceptable problem resolution: *Was a solution to the problem achieved? Was action taken? Was the created media resource useful?*
- 4) Fairness, ontological authenticity, educative authenticity: Provides a framework to evaluate how the researcher functioned and worked with members of the advisory team (Guba & Lincoln, 1989).

## 49. Methodological rigour

To determine methodological rigour one can look at credibility, transferability, dependability and confirmability (Guba & Lincoln, 1989). Three processes were employed to ensure the data were perceived as credible and believable by those who participated in the study.

**Credibility:** First, there was a period of prolonged engagement in order to develop trust between me and the community participants. This included substantial partnership development. As a result actual filming did not commence until two years after the project was first discussed with the community. This ensured community buy in and that cultural protocols (tikanga) had been adhered to. Second, member checks were initiated with all of the key informants and hui (focus groups) participants to ensure accuracy. All participants were offered the opportunity to amend or qualify their transcripts. Third, peer debriefing occurred at every stage of the research. I discussed the findings with the Community Advisory Board, and members of the local supporting PHOs to get their grassroots perspective. This included writing reports for community groups in non-academic language to encourage a broad range of feedback. In addition, I made presentations at community hui. I also discussed the research with my supervisors to assure academic rigour.

**Transferability:** Lincoln and Guba (1985) recommend providing “thick” description of research data so that another reader has enough information to apply in a different research context. However, as Mendenhall et al. (2010) point out, CBPR is primarily focused on the generation of local knowledge and producing social change in local communities. Each community will be distinct, unique and complex. What is transferable is the description of the research *process* rather than the findings per se. The research process described in the methodology and results chapters outlines the various methodological steps taken. This process included steps taken to ensure community involvement (for example grass roots networking and the creation of a CAB) and a qualitative research design incorporating key informant interviews and hui. I have also made clear how this research informed the direction and content of the documentary resource and the behavioural theory selected.

**Dependability and confirmability:** Lincoln and Guba (1985) recommend documenting all stages of the research process including data collection and analysis. They also recommend establishing a transparent audit trail for the research data and reducing bias by regularly sharing data and interpretations with others. For this study all of the data was imported and coded and memoed in a project unit using Atlas ti software. First observations and initial interpretations of

data were recorded in memos and linked to the corresponding transcript. To facilitate partnership analysis and interpretation of the qualitative data, I first grouped key informants' and hui participants responses according to answers. I also made some initial observations that could be used to generate discussion and analysis. After each stage of the research was completed, two meetings were held with the Community Advisory Board to discuss and analyse the findings. At the first meeting we discussed the descriptive coding and at the second the thematic coding and additional feedback from people they had shared the community reports with.

### **Evaluation of the application of indigenous principles**

**Principle 1, Reflection:** Walters et al. (2009) define reflection as *the process of examining the privileged statuses from which partners frequently operate*.

A key tenet of CBPR is that researchers need to reflect on the influence of their own power (race, gender, education, class, sexual orientation, religion) on the research relationship (Israel, Eng, et al., 2005; Wallerstein & Duran, 2006; Wallerstein & Duran, 2008). Accordingly this process of reflection relates to the fourth evaluation criteria – evaluating how I functioned and worked with members of the advisory team. In considering ontological authenticity, the researcher needs to consider how their own perceptions and worldviews have changed or developed throughout the course of the research. To do so it was necessary to reflect on and consider cultural humility and cultural safety.

As detailed in my methodology chapter, leading CBPR academics emphasise the concept of cultural humility in order to address potential power imbalances between researchers and community collaborators (Chávez et al., 2008; Israel, Eng, et al., 2005; Minkler, 2004; Wallerstein & Duran, 2006). Researchers will never be able to achieve cultural competence in another's culture and subsequently the goal should be to achieve cultural humility (Tervalon & Murray-Garcia, 1998). This requires the researcher to participate in an on-going process of self-reflection and critique in which one examines and assesses power relations, bias, racism. It also requires the researcher to be humble, respectful, open, willing to listen and learn, and to be committed to address inequality in the community in which they work (Israel, Eng, et al., 2005; Wallerstein & Duran, 2006).

Further, by anticipating potential differences with research collaborators and setting up mutually agreed upon processes to resolve issues, researchers can honour the concept of cultural safety by creating “an environment that is spiritually, socially and emotionally safe, as well as physically

safe for people...It is about shared respect, shared meaning, shared knowledge and experience of learning together” (Williams, 1999, p. 213).

**Evidence:** Throughout the research process I wrote a number of personal memos reflecting on how my differences from the community might influence or bias my understanding. For example, I was relatively new to the country when I began the research and although I had previous experience working with indigenous cultures, my understanding of Māori culture was initially limited. As a result of this recognition I sought guidance and mentorship from Kaumatua (Māori elders). Kaumatua support and guidance not only helped educate me about cultural protocols but when Kaumatua also accompanied me to some initial meetings, it ensured that some sceptical audiences were open to listening to my requests for help or collaboration. As documented in Chapter IV, Kaumatua support was maintained over the course of the research with elders serving on the CAB as well as participating in the documentary filming.

As I reflected on the early stages of community networking I recognised that being transparent went a long way in gaining trust. This required being open about what I did not know, always being willing to learn, and as important being able to admit when I made mistakes. Reflecting on the research process also helped me not to take slights personally. I learned to appreciate that not everyone would be enthusiastic about the research and that some people I encountered would be sceptical of both the research and my intentions. Conversations early in the process with some health workers confirmed a concern commonly found in indigenous communities that they are subject to the whims of “parachute researchers” who drop in to communities take what they want and leave (Mohammed et al., 2012). Research with Māori has been characterised by an absence of shared decision making and a failure to adequately encompass and include Māori views (Blundell et al., 2010; Durie, 1999). As Linda Tuhiwai Smith (2005) has observed, from an indigenous perspective research is equated with the history of colonisation and is deeply connected to questions of power.

This led to probably one of the most important lessons that I learned in the reflective process. Gaining trust takes time. At first I would frequently get frustrated at what I perceived to be the length of time it took to achieve tasks that I thought would not or should not take long (for example, getting my calls or emails returned). I gradually realised that my research timetable was not going to be the priority for many over committed community members who already had a hard time juggling numerous work, family and community commitments. This was further exacerbated by the Christchurch earthquakes which saw considerable disruption and personal stress to people’s homes and workplaces. Many people left Christchurch, workplaces were

destroyed, jobs lost and families displaced. When I returned to the research after a five month pause I was humbled that all of the CAB were willing to re-engage with the research. From that point on I made sure I built in plenty of time for each stage of the research. I was reminded of Linda Tuhiwai Smith's argument that "idealistic ideas about community collaboration and active participation need to be tempered with realistic assessment of a community's resources and capabilities, even if there is enthusiasm and goodwill." (Smith, 1999, p. 140).

Reconceptualising my understanding of time and study time frames also helped me appreciate what I was hearing from the key informants. This relates to another aspect of evaluation criteria (4) educative authenticity, seeing one's understanding of other's perceptions change or develop. For example, one of the key informants talked about having an appointment book with half as many appointments as Pakeha nurses. I learned that just as I had needed to gain people's trust the same was true of the nurse's relationship with her patients. For this nurse conveying medical facts was second to *whakawhanaungatanga*, building relationships with the *whanau*. Learning to appreciate that earning trust takes time helped me recognise and conceptualise what the nurse was telling me as a service barrier and a possible reason why Māori were not engaging in diabetes services. Indigenous knowledge and understanding is modelled on a holistic approach and as Blundell et al. (2010) have noted, both health worker and participant regard appointments as social occasions to discuss family, emotional and spiritual aspects of health and wellbeing.

In reflecting on this I was reminded of Pyett et al.'s (2008) observation that

If we are genuine about including communities in the research endeavour, and if we go about things respectfully and with patience, taking the necessary time to develop relationships of mutual trust and shared understanding, we are contributing to the process of de-colonising research (Pyett et al., 2008, p. 181).

I also reflected on the influence of my race and gender on the research process. This reflection also led to a modification of the research design. One of the key Informants had commented to me that not only am I Pakeha (non-Māori) but I also have a different body type to many Māori. He suggested this might influence how people talked (or perhaps did not talk) with me about their experience with diabetes. This conversation influenced the decision to have CAB members lead the *hui*. Although I was first concerned that I might be compromising the research design, I concluded it was the right approach as it would encourage *hui* participants to speak more freely about their experiences. In revising my approach to the *hui* I reflected on Foucault's conceptualisation of power (see methodology chapter 17.2). Foucault argued that at every level

(family, community, institutional) there are discussions and practices that both maintain but also challenge the dominant power structure and ways of thinking about and acting in the social world (Foucault, 1977, 1980). I reminded myself that my research was not going to satisfy a positivist tradition concerned with validity. But by ceding control of the hui and incorporating community knowledge claims into the scientific processes I would, as Minkler and Corage Bandon (2008) have previously argued, “shift not only the shape and direction of the research but, more fundamentally, the power dynamics of science production itself.” (Minkler & Corage Baden, 2008, p. 254).

Cultural safety was ensured within the CAB when we all verbally agreed at the first meeting that all members of the team were equal and everyone’s views were to be solicited and respected. It was also agreed that all analyses would be discussed with the CAB in order to ensure accurate interpretations and to avoid harm and that the created resource would build on and highlight community’s strengths and be relevant and acceptable to the community. The establishment of the CAB as a whānau of interest (Bishop, 1999) reinforced the collaborative nature of the research and ensured that cultural protocols were honoured.

**Principle 2, Respect:** As Tuhiwai Smith (2005) has argued, the common understanding of the values of respect has been narrowly framed by a Euro-American perspective. Walters et al.’s (2009) thinking is more inclusive and defines respect as *partners valuing and prioritising indigenous epistemologies, knowledge, cultural protocols, and healing practices*. This principle relates to fairness, the fourth evaluation criteria. Fairness considers the extent to which the perceptions and worldviews of all the participating stakeholders are requested and respected.

As previously discussed in the methodology chapter, participatory research shares some similarities with Kaupapa Māori critiques of the Western research paradigm. Although I will argue that this study valued indigenous epistemologies and cultural protocols it is important to again note that there remain some significant differences with Kaupapa Māori. For many of these scholars, te reo (language) is central to Kaupapa Māori and the conceptualisation of Māori knowledge (Nepe, 1991; G. Smith, 1992). While some scholars have noted similarities between Kaupapa Māori and participatory approaches (Eketone, 2008; Mahuika, 2008), Bishop (1998) has cautioned against equating the two. While the evaluation framework I have selected would be criticised by Bishop as being determined by me rather than in accordance with Māori cultural practice, I suggest that the incorporation of these eight indigenist principles share some similarities with a Kaupapa framework. As Mane (2009) has argued, there are some important similarities between CBPR and Kaupapa Māori. Both value research that is driven and led by

those directly affected by the issues. Both research approaches can support self-determination and well-being. Both validate local knowledge and expertise. Both have the goal of bringing positive change to the community.

**Evidence:** As previously described in the results chapter, one of the ways indigenous knowledge and cultural protocols were prioritised was by basing the approach to the CAB on the concept of whanaungatanga (togetherness). As Bishop (1998) explains, whanaungatanga is one of the fundamental ideas within Māori culture guiding one on how to establish and maintain research relationships and orienting the researcher to understanding that their research requires ethical, moral and spiritual involvement. Following Bishop's recommendations the CAB was structured as an extended family, what Bishop calls a 'whanau of interest.' Meetings began with a karakia (prayer) and the sharing of food. Decisions were made as a group and approved by Kaumatua. The sharing of food at both CAB meetings and research hui was integral to cultural understanding and protocol. Manaakitanga (hospitality) is a cornerstone of Māori tradition. As Blundell et al. (2010) have emphasised, understanding and respecting what appears to simply be an everyday activity, is in fact key to establishing trust with participants. As they describe it.

Manaakitanga is a very powerful way of expressing how Māori communities may care for one another. Manaakitanga is a feeling; it implies a responsibility upon a host; an invitation to a visitor. Manaakitanga seeks common ground upon which an affinity and sense of sharing can begin (Blundell et al., 2010, p. 2).

And as L. Smith (2005) and Cram (2001) have argued embracing this value allows knowledge to flow both ways. The researcher is not simply gathering data, they are a learner. Just as it was important to share food, it was important to share results. Thus the concept of manaakitanga was intrinsic in the writing and sharing of community reports. As Cashman et al. (2008) have found, in many CBPR studies communities are not typically involved with data analysis. Israel et al. (2005) emphasised that it is essential that results are fed back in ways that are both understandable and useful. Cashman et al. (2008) have recommended engaging community partners' involvement with the analysis by displaying data in easily understood formats like coded transcripts. Consequently, I wrote reports in non-academic language to be shared with the CAB.

Blundell et al.'s (2010) account of some of the challenges they faced when working on a diabetes intervention with Māori were instructive in informing my understanding of tikanga (cultural protocols). For example, they underlined the importance of the process of

whakawhanaungatanga, “the cultural values, customs and practices which encompass and link the family unit as a collective.” (Blundell et al., 2010, p. 3). This proved to be important as this process was similarly emphasised by some of the key informants as critical to their work. As one nurse observed, she might not even mention the word diabetes until the second or third meeting. Likewise, the CAB facilitators approached the hui not simply as a forum to gather research data but as a social gathering for the wider discussion of family and emotional and spiritual matters. This social interaction was not only appropriate, it in turn led to richer data. Similarly Blundell et al. (2010) emphasised the cultural importance of whānau leading whānau as to do so promotes the concept of Mana Whakahaere (independence). This was also emphasised in my research by the CAB, key informants and hui participants, and subsequently became the central focus of the documentary. The emphasis on whānau was integral to the success of the documentary. One of the CAB members observed this enhanced the acceptability and reception of the documentary messaging (see Appendix J).

My research approach acknowledged that the status of Māori health cannot be understood independent of the history of colonisation and the impact of colonisation on socioeconomic and sociocultural development (Robson & Harris, 2007; L. Smith, 2000; L. Smith, 2005). Consequently an understanding of Māori health cannot be rooted in a Western medical model which treats the individual’s mental and physical health as separate entities. At every stage of the qualitative research questions were included that encouraged a discussion of health that incorporated the Whare Tapa Wha Model developed by Mason Durie (1998). This was important because incorporating an understanding of this model widened the discussion to reveal significant service barriers as identified by both key informants and hui participants (see results presented in Chapter V 29. and VI 38).

This model also informed the direction and content of the documentary resource. For example, the primary focus on making health changes for the sake of the moko and mokopuna (children and grandchildren) reflects one of the four dimensions of Māori wellbeing Taha whānau (family health). The other dimensions of Māori wellbeing, Taha tinana (physical health) Taha wairua (spiritual health) Taha hinengaro (mental health) were also incorporated into the messaging. See Appendix I and documentary for detailed examples.

**Principle 3, Relevance:** Walters et al. (2009) define relevance as *the community should contribute to defining research problems and strategies in response to their own self-identified needs and concerns.*



This principle relates to the second and fourth evaluation principle. In determining the level of community involvement throughout the research process one should consider the principles of catalytic and tactical authenticity. The former looks at the extent to which action is promoted by the research process; the latter the extent to which stakeholders are encouraged to act.

**Evidence:** From a research design perspective, community input was requested at every stage. Community input was sought to ascertain whether there was a need for a resource and whether the research design was appropriate. Advice from a number of community members helped determine that the focus of the resource and research priority should be on prevention rather than management. One of the CAB members described the consultation process as follows

Alison actually consulted and listened to community members at all stages and quickly gained the trust that many researchers do not achieve. She tirelessly engaged in active participation and asked community members to help define research questions and strategies- a first time for many of us to be asked to contribute to research in this way! (See Swindells letter, Appendix J for further details).

The qualitative research design helped ensure that the community voice was central to the research. As previously noted, recognising and respecting the issues and priorities identified by key informants is a major CBPR principle. Key informants are important because as Eng et al., (2005) argued, their understanding of the history and culture of the community provides a wealth of data for planning and identifying health initiatives. Yet their insights are frequently overlooked by researchers in favour of statistical data when identifying community needs and health solutions. Requesting and respecting key informants opinions was not only a fair approach, it also revealed a more complex health narrative than that demonstrated by statistics. While statistical data can demonstrate that diabetes is a severe problem in the community, in depth interviews and hui revealed why. Participants described often complex historical, structural, economic, and social reasons for poor health and high rates of diabetes in the Māori community. The key informants contributed to and shaped the questioning for the group. For example, a consistent theme from the key informant interviews was that fear and denial are a defining characteristic of their clients' experience with diabetes. Several key informants suggested adding a question about this to the hui guide. Likewise, questions about exercise were modified based on key informant advice. For example, the word exercise was replaced by the word movement (See Appendix F for further examples).

Importantly, tactical authenticity was incorporated into the design of the hui and CAB members recruited for and led the discussions. As Kieffer et al. (2005) have argued, many researchers consider focus groups conducted under the guidance of a moderator to be a culturally sensitive method and particularly appropriate for cultures that value collectivity. It has also been argued that the group dynamic may empower participants, by not only encouraging the free flow and exchange of ideas between participants but also potentially impacting the balance of power between the moderator and participants (Madriz, 2000). As with the interview method, participants express themselves in their own words and language (Gettleman & Winkleby, 2000). By selecting to have the moderators be members of the community that shared a similar demographic profile, the perceptions and worldviews of hui participants were prioritised. Again this helped ensure richer data as people spoke more freely than they would have if I led the discussions.

Relevance was also key to how I approached the documentary. The community led the recruitment of participants for the film (catalytic authenticity) with several community groups and Māori health providers making recommendations. The CAB also actively consulted on the treatment and storyline and a small group of community members offered additional feedback on the edit. The utilisation of a documentary storytelling approach is a good example of tactical authenticity. Kieffer et al. (2005) previously found that telling stories allows participants to become “agents of change” as members share perspectives on health and offer strategies to address their concerns that are rooted in the realities of their everyday experiences. Similarly, all of the people featured in the documentary offered positive messages encouraging fellow community members to act to positively affect health change. Catalytic authenticity was also inherent in the way the central whānau in the film were encouraged to make changes. The potential health improvements the family could make were determined by a whānau worker and the family together. This ensured cultural relevance and a realistic plan the family were more likely to attempt.

**Principle 4, Resilience:** Walters et al. (2009) state that with resilience *all aspects of the research must acknowledge the community's strengths.*

This is a significant principle in the New Zealand context, because as Bishop (1998) has argued, a social pathology research approach has perpetuated colonial values and reinforced an ideology of cultural superiority where Māori are frequently depicted as unable to cope. Likewise, Pyett et al. (2008) have argued that the communications focus of research needs to be reversed from a deficit model of health to one that places primacy on communicating positive stories from the

community. Adopting a holistic model of health can reframe health promotion away from positioning indigenous people as a problem to highlighting community strengths and resilience.

**Evidence:** At every stage of the research this message was reinforced. As explained in the results chapter, key informants and hui participants wanted a documentary narrative with positive and realistic messaging. Not only was this culturally appropriate it was methodologically appropriate and was incorporated into message design with the adoption of Bandura's social learning process. Bandura (1986) believed that how people think and behave is determined by their confidence in their ability to execute a successful course of action. The rationale for the theory employed in the documentary was that self-efficacy can be influenced by the communications process. Subsequently the film contained positive examples of success communicated through vicarious efficacy, persuasory efficacy and the setting of realistic personal goals. In doing so, the goal was to promote positive action in the viewers (catalytic and tactical authenticity) and encourage them to believe that diabetes is preventable and not a death sentence (See script Appendix I for specific examples). The emphasis placed on positive messaging was acknowledged by one of the CAB members who commented "Another wonderful change for me personally was the way Alison worked on community strengths rather than highlighting problems or negative stereotypes. She paid attention to the social, cultural and economic conditions that influence health." In her letter she goes on to describe the positive audience reaction she witnessed at a community screening of the documentary (See Swindells letter, Appendix J for further details).

**Principle 5, Reciprocity:** Walters et al. (2009) state that *the partnership needs to be collaborative and mutually respectful with knowledge exchanged in both directions*

**Evidence:** As previously discussed, structuring the CAB as a whānau of interest helped ensure cultural humility and cultural safety. A letter from Wayne Smith, one of the CAB advisers details how he viewed the partnership and the role of the CAB as, "ensuring content was acceptable, relevant, and an appropriate process was being adhered to." He also describes the trust that developed between me and the CAB members (See Smith letter, Appendix J for further details). In exchange for community input and support for the research I offered tangible things in exchange. I promised to write up and present the research findings in accessible and non-academic language, to present when requested at community forums and to ensure that the documentary resource could be widely and easily distributed. For example I worked with He Oranga Pounamu and Pegasus Health to ensure two hundred copies of the DVD were distributed to members of the community and Māori health providers. Copies were also shared at a Diabetes

Nurses Symposium and with hospital staff at District Health Boards for training purposes. Beyond the tangible assets it was just as important to offer my respect and my word. This included honouring all promises made. I found this to be an essential part of building relationships with the CAB (see Appendix J letters of support).

**Principle 6, Responsibility:** Walters et al. (2009) state that *partners are obliged to enhance community capacity to conduct indigenous and Western research, disseminate findings in culturally meaningful ways, and anticipate their implications.*

**Evidence:** As discussed above, the community was encouraged to participate in the research in several ways. For example, key informants were instrumental in shaping the direction and working of the hui guide. The CAB led the hui and also participated in the initial analysis of the data, the documentary approach and storyline and the offline edits of the documentary film. To facilitate CAB analysis and community feedback, I created easy to read reports and initially grouped interview transcripts and responses according to answers. This was important to do for two reasons. First it helped facilitate partner analysis. I followed advice to display data in easily understood formats to make it understandable (Cashman et al., 2008). Doing this was also important from an epistemological perspective and stays true to the emancipatory critique of power inherent in CBPR. As Wallerstein and Duran (2008) have argued, highly specialised academic research language can be repressive and constrain how communities interact with researchers. By reporting the data this way I could encourage joint decision making and social action (catalytic and tactical authenticity). For example, CAB expertise was essential in negotiating an in-depth discussion of barriers to physical activity and healthy eating (see Chapter V). As important, by producing community reports results could be easily shared with Māori health providers, and PHOs. As Jane Cartwright (Community Development Programme Director at Pegasus Health) commented the research “has added to the debate about how to work with this community to improve health outcomes” (See Cartwright letter, Appendix J for further details).

**Principle 7, Retraditionalisation:** Walters et al. (2009) state that *traditional knowledge and methods must be integrated actively into the formulation of research questions and the process of scientific inquiry.*

**Evidence:** There were several ways that traditional knowledge was integrated. As discussed above Kaumatua support, knowledge and guidance was integral to the process and Kaumatua approval was sought at every stage of the research. The CAB was structured as a whānau of interest and the process based on the concept of whanaungatanga (togetherness). This requires

the researcher to understand their research requires ethical, moral and spiritual involvement. For example, meetings began with a karakia (prayer). And as described above the sharing of food at both CAB meetings and research hui was integral to cultural understanding and protocol. Manaakitanga (hospitality) is a cornerstone of Māori tradition. The whānau of interest model also emphasises collective decision making. For example, the decision to have the CAB members lead the hui was made after we all agreed that this would be the best way to encourage community members to speak openly about their experiences. This also enhanced cultural protocol as the CAB members did not simply treat the hui as a data gathering exercise. They took a more holistic approach and the hui was a social occasion to discuss family and the emotional and spiritual aspects of health and wellbeing.

Respect for traditional knowledge is integral to CBPR's epistemology. Like Kaupapa Māori research, CBPR challenges the idea of objectivity and sees science as a social construct and an ideological process that often supports the status quo (Wallerstein and Duran 2008). CBPR incorporates multiple ways of seeing the world and as Fletcher (2003) noted, is an important tool for researchers working with indigenous populations because it acknowledges different ways of knowing and gives equal weight to scientific and cultural expressions of knowledge. From a Kaupapa Māori perspective the incorporation of traditional knowledge into my research design would probably be criticised and this points to one of the limitations of this study. To scholars like Bishop (1998), giving equal weight to scientific and cultural expressions of knowledge would not go far enough. As discussed in the methodology chapter, Russell Bishop (1998) cautions that Kaupapa Māori should not align with participatory approaches. He believes there is a danger in equating the Māori concept of self-determination (tino Rangatiratanga) with participatory methodological approaches. Bishop (1998) argues there is a danger in what he refers to as an "international methodology of participation." He highlights the language of research (objectivity, replicability, validity) and how the use of this language can create space for outside researchers to determine and control what constitutes reality for participants. Bishop (1998) argues that even what Lincoln and Denzin (1994) describe as a post-positivist frames of reference, as well as the use of non-Māori methodological frameworks, continues a tradition of outside researchers determining what is valid for Māori.

**Principle 8, Revolution:** Walters et al. (2009) define revolution as *partners must actively seek to decolonize and indigenize the research process to transform science, as well as themselves, their communities, and larger society for the betterment of all.*

Like other CBPR studies, my research is based on an ecological approach that recognises a documented history of health inequalities based on race, ethnicity, class and gender and incorporates the active participation of the community in addressing these health problems (Green et al., 2001; Minkler & Corage Baden, 2003; Schulz et al., 1998; Sullivan et al., 2001). Because CBPR places primacy on power sharing and achieving social action and change, it is a good fit for work with minority communities who have felt shut out of the decision making process (Israel et al., 2005; Horn et al., 2008). Pyett et al. (2008) have suggested that to de-colonise research it is not necessary to invent new research methods, but it is important to place primacy on values, processes, and relationships. They argued that health promotion interventions need to have tangible outcomes (posters, videos, community reports) that the community actually wants. (Pyett et al, 2008, p. 181). By following these recommendations and employing indigenist principles we produced a documentary that has been viewed and accepted by the target community and embraced by the CAB and funders (see Appendix K letters of support). It has also contributed to the debate within the health care system about how to best work with the Māori community to improve health outcomes. After further consultation with CAB members and funders we have agreed that the recommendations to health professionals, promoters and educators and planners outlined in Chapter VIV should be shared at a national level. While the DVD has been shown to groups of local GPs and acquired by other District Health Boards, the research findings and DVD will also be shared with the Ministry of Health and The Royal College of GPs.

**Table 4. Indigenist Principles: Evaluation**

Indigenist Principles Walters et.al. (2009)	Examples of	Evaluation criteria	Evidence
<b>Reflection-</b> examining the privileged statuses from which partners frequently operate	Reflective diary and memos. Ensuring cultural humility and cultural safety	Ontological & educative authenticity	1. Kaumatua support 2. Revised study deadlines to better reflect & accommodate community's time frame 3. Revised study design: CAB members led hui

<b>ii) Respect</b> -partners valuing and prioritizing indigenous epistemologies, knowledge, cultural protocols, and healing practices	<p>Establishment of CAB as whānau of interest.</p> <p>Respecting tikanga (protocol).</p> <p>Incorporation of Whare Tapa Wha model of health and emphasis on whānau</p>	Fairness	<ol style="list-style-type: none"> <li>1. Hui protocol. Incorporated whakawhanaungata nga, not simply data gathering</li> <li>2. Co-analysis of data</li> <li>3. Manaakitanga prioritised. Sharing of food and sharing of research (e.g. community reports)</li> <li>4. Documentary messaging: whānau leading whānau</li> <li>5. See letters of support (Appendix K)</li> </ol>
<b>(iii) Relevance</b> - the community should contribute to defining research problems and strategies in response to their own self-identified needs and concerns	<p>Community consulted on</p> <ul style="list-style-type: none"> <li>• Research design</li> <li>• Documentary focus</li> <li>• Shaping hui questions</li> <li>• Leading the hui</li> <li>• Interpreting data</li> <li>• Structuring health approach for whānau in film</li> <li>• Distribution strategy for films release</li> </ul>	Fairness Catalytic & tactical authenticity	<ol style="list-style-type: none"> <li>1. See Swindells letter of support (Appendix K)</li> <li>2. Key informants shaped hui questions (See Appendix F)</li> <li>3. CAB members led hui</li> <li>4. Community groups recruited documentary participants</li> </ol>
<b>(iv) Resilience</b> - all aspects of the research must acknowledge the community's strengths	<p>Positive messaging of film was informed by the community. Vicarious efficacy, persuasory efficacy and the setting of realistic personal goals.</p> <p>Film had positive call to action</p>	Fairness Catalytic & tactical authenticity	<ol style="list-style-type: none"> <li>1. See Script examples (Appendix J )</li> <li>2. See Swindells letters of support (Appendix K)</li> </ol>
<b>v) Reciprocity</b> - the partnership needs to be collaborative and mutually respectful with knowledge exchanged in both directions	<p>Community offered knowledge and support.</p> <p>Researcher offered filmmaking and media expertise.</p> <p>Researcher wrote up research in non-academic language</p>	Educative authenticity	<ol style="list-style-type: none"> <li>1. See Smith letter of support (Appendix K)</li> <li>2. Collaborated with health providers to ensure community wide distribution of documentary</li> </ol>

<p><b>(vi) Responsibility</b> - partners are obliged to enhance community capacity to conduct indigenous and Western research, disseminate findings in culturally meaningful ways, and anticipate their implications</p>	<p>Community participated in</p> <ul style="list-style-type: none"> <li>• Shaping hui questions</li> <li>• Leading the hui</li> <li>• Interpreting data</li> <li>• Structuring health approach for whanau in</li> </ul> <p>Researcher wrote up research in non-academic language</p>	<p>Catalytic &amp; tactical authenticity</p>	<ol style="list-style-type: none"> <li>1. Community consultation at every stage of research</li> <li>2. Hui protocol. Incorporated whakawhanaungata nga, not simply data gathering</li> <li>3. Co-analysis of data</li> <li>4. Sharing of research reports in non-academic language</li> <li>5. See Cartwright letter of support (Appendix K)</li> </ol>
<p><b>(vii) Retraditionalization</b> - traditional knowledge and methods must be integrated actively into the formulation of research questions and the process of scientific inquiry</p>	<p>Incorporation of Whare Tapa Wha. Establishment of CAB as whānau of interest.</p>	<p>Ontological &amp; educative authenticity</p>	<ol style="list-style-type: none"> <li>1. Kaumatua guidance at every stage</li> <li>2. CAB structured as whānau of interest</li> <li>3. Incorporation of Manaakitanga</li> <li>4. Documentary messaging: whānau leading whānau</li> </ol>
<p><b>(viii) Revolution</b> - partners must actively seek to decolonize and indigenize the research process to transform science, as well as themselves, their communities, and larger society for the betterment of all</p>	<p>Film is tangible result of research. Has added to debate about how to improve health outcomes (see Cartwright letter)</p>	<p>Catalytic &amp; tactical authenticity</p>	<ol style="list-style-type: none"> <li>1. Over 200 copies of DVD distributed in community</li> <li>2. Policy implications to be shared with Māori health providers, DHBs, Ministry of Health and national medical organisations (e.g. Royal College of GPs)</li> </ol>

In the final chapter of my thesis I will summarise the research findings and explain how my research adds to current understanding about how to create culturally appropriate health promotion materials for Māori. This discussion will include a recommendation to researchers to



adopt Walters et al.'s (2009) eight indigenist principles in their research design. Particular attention will be paid the challenges and limitations of CBPR and I will make recommendations for future research. The thesis will conclude with some practical policy recommendations informed by my research findings.

## **Chapter VIV Discussion**

### **Chapter Overview**

In this final chapter of the thesis I will summarise the research gaps that I identified at the beginning of the research process. I will outline what I learned that is consistent with the literature, identify some new findings, and explain how my research adds to current understanding about how to create culturally appropriate health promotion materials for Māori. In doing so, I will highlight both the strengths and limitations of my study. I will make recommendations for future research as well as provide some reflection on the challenges of my research that might prove useful to other researchers contemplating CBPR projects with Māori. I will conclude the thesis with some recommendations to policy makers. My research findings might be useful to medical practitioners, health promoters and health managers and planners.

This study identified two related problems with past attempts at producing health promotion and education materials about type 2 diabetes for Māori. These can be summarised as follows.

**Problem 1:** A failure to employ culturally appropriate research methods when creating type 2 diabetes health promotion materials for Māori. Subsequently there was a need for culturally appropriate communication to reflect Māori beliefs and practices.

The low level of Māori knowledge of diabetes has been attributed to a failure to provide information that reflects Māori cultural practices in ways that are appropriate for use in Māori communities. Conventional approaches are insufficient when dealing with a high risk population like Māori and it has been argued that more attention needs to be paid to where and how health education is delivered (Simmons et al. 2004). This is supported by international literature that has also demonstrated a need for health promotion materials that recognise and engage with the social context that effects racial and ethnic inequalities in health (Nazroo & Williams, 2003). Several studies of Māori Health have identified the need for innovative models and approaches to diabetes education in order to reduce the disparities between Māori and non-Māori disease rates (Healt Funding Authority, 2002; Ministry ofHealth, 2009; Robson & Harris, 2007).

**Problem 2:** Difficulty in ascertaining what constitutes a culturally appropriate research process or suitable health behaviour theory when designing health promotion materials for type 2 diabetes with Māori. Subsequently there was a need to make explicit the research process and employment of theory in the design of health promotion and education material.

Literature on health communication has made clear the need for increased focus on the unique characteristics of racial and ethnic groups in order to address the persistence of health disparities (House & Williams, 2000; Resnicow et al., 2002). Resnicow et al. (2002) argued that the success of health education materials will depend on culturally relevant design that includes close attention to historical, social and environmental barriers, as well as community norms, behaviours values and beliefs.

In the literature review I discussed two major type 2 diabetes prevention programmes in New Zealand with a media component, Ngati and Healthy and Let's Beat Diabetes. For both studies complete information about the consultation process with Māori and attention paid to culturally relevant design and use of health behaviour theory could not be acquired. For Ngati and Healthy, the data that informed the health promotion initiatives was generated from a baseline prevalence survey. The questionnaire accounted for demographic information and limited information about exercise and diet that informed the created media. The quantitative design did not account for cultural explanations about community values, beliefs or behaviours. Ngati and Healthy employed a participatory model when designing the next stage of communication messages, but there have been no published papers detailing the model, exactly how community involvement was solicited or how the process was evaluated. The literature review detailed several limitations to how the Let's Beat Diabetes campaign worked with Māori. These included a failure to quickly respond to community concerns about inappropriate campaign messages, to pre-test messages, and to tailor messages (McNeill et al., 2008). McNeill et al.'s recommendations substantiate the need for culturally relevant design in their call for basing health promotion materials on Māori experiences, values and needs. This they suggested would require the use of focus group rather than survey data.

I also discussed that it is often difficult to ascertain what makes for an effective educational resource because many authors fail to identify theory when discussing health communication interventions with ethnic or racial groups (Randolph & Viswanath, 2004). Several studies have shown that effective health communication interventions use theory not only to develop and shape messages but to ultimately ensure behaviour change (Kennedy & Abbatangelo, 2004; Noar, 2006; Wallack & Dorfman, 2000). Further, an expert panel convened by the Centers for Disease Control and Prevention concluded that health interventions targeting a specific racial or ethnic minority group should pay particular attention to theory selection because some theories can be a poor fit with the realities of vulnerable populations (Kennedy & Abbatangelo, 2004). The literature review demonstrated that this is true in New Zealand. Although Ngati and Healthy

employed a participatory model and community input was sought, neither behavioural change theory nor health communication theory was employed in the crafting of the messages (K. Coppell, personal communication, September 18, 2013). With Let's Beat Diabetes, it was impossible to definitively ascertain to what extent health behaviour theory was employed (McNeill et al. 2008). Similar limitations were identified in the production of diabetes awareness videos. These included failure to employ behavioural theory, modification of content rather than tailored content, lack of formative research, absence of narrative and lack of awareness of tikanga Māori (protocol).

From this review I concluded the following:

There remains a gap in understanding and that part of the study should focus on how Māori understand and make sense of diabetes as well as the social and cultural meanings given to the disease. I reasoned that by first comprehending this I could then design a culturally appropriate educational resource.

I further noted that there have been only a few video digital resources about diabetes produced for Māori even though Ministry of Health reports support their use as an effective educational tool (Ministry of Health 1994, Public Health Commission, 1997). None of the produced resources to date have employed behavioural theory. I therefore concluded that there was another research gap and that my study should make explicit the use of theory to inform and shape the communication messages in the new resource.

I then outlined an argument for employing CBPR in the creation of a digital media resource. I argued that digital storytelling can be a culturally sensitive form of communication. I explained how following CBPR principles can reflect the cultural values and behavioural preferences of indigenous communities, and I supported this argument with pertinent examples from the international literature.

My research objective was to ascertain whether Community Based Participatory Research (CBPR) employed in combination with proven health communication principles and behavioural theory could be used to create an appropriate resource for Christchurch adult Māori at risk for type 2 diabetes. The research would focus on the community development process of working with an indigenous population to develop a health promotion resource that reflected Māori beliefs and cultural practices.

In doing so I would answer the research question: How can CBPR and behavioural theory best be employed to create a culturally relevant digital media resource for knowledge awareness and behaviour change for adult Māori at risk for type 2 diabetes?

## **50. Māori knowledge and understanding of diabetes**

My research findings were consistent with existing statistical data that have shown a low level of knowledge and awareness about type 2 diabetes in the Māori community (De Lore et al., 1993; Kirkwood et al., 1997; Simmons & Voyle, 2003; Wyllie & MacKinlay, 2007). This qualitative study adds to this understanding by explaining some of the reasons *why* this is the case. In doing so this study contributes to the small body of international literature concentrating on the perception and lay understanding of diabetes within Aboriginal communities and the social and cultural meaning given to the disease (Satterfield et al., 2003). This contribution is important because when it comes to planning and implementing interventions targeting type 2 diabetes, lived experience is a key consideration and one that remains under-developed. By employing key informant interviews and hui in the research design I was able to gather rich data about historical, social and environmental barriers, as well as community norms, behaviours, values and beliefs. Participants described often complex reasons for poor health and high rates of diabetes in the Māori community.

Three pertinent examples from the research data highlight that in order to explain and understand diabetes and design appropriate interventions, it is necessary to take culture into account. As one of the key informants observed.

*Our people think in terms of big is good. So large quantities of food on the plate. So it's changing that thinking the manaakitanga. There's that cultural aspect that you would never want someone to leave your home and say oh well they didn't feed me much.*

This quote underscores how cultural beliefs and values have a powerful influence on the diet and weight behaviours of some Māori. For as Mason Durie (2001) has previously observed, larger body types and a biomedical understanding of obesity do not carry the same stigma with Māori. In this instance, the culturally accepted thinking that a good host will provide a lot of food at social gatherings can often impede whanau's attempts to improve health decisions.

In the literature review I argued that one of the limitations of epidemiological research is the failure to acknowledge the impact that Pakeha colonial practices have on Maori health. However, the following comment from one of the Hui participants underlines that it is important to

recognise that for some Māori, diabetes is inseparable from a colonised history that continue to inform family lives and cultural practices.

*See we don't get mataitai anymore. We can't just go to the beach and go on the rocks and get it because we don't know what's healthy and unhealthy on our beaches anymore*

The Hui conversations showed that that threat of death as an outcome of poor health does not have the same resonance as it does with Pakeha culture. Rather, good health was understood as a collective responsibility and being present in the lives of grandchildren positioned as the appropriate reward. As one Hui participant stated to nods of approval.

*Māori have a different concept about death and dying. You know right up until about five years ago I had my funeral planned. Everything was in place and it was okay for me to die because I know where I am going to and who I am going to see. So it was never a big issue about me dying. Except for my favourite moko, I've got ten of them and a great grandchild, but I decided I actually really want to be around at their twenty-first and how do I do that without changing something?*

Pakeha society emphasises individual lifestyle choices as central to good health (Hodgetts & Chamberlain, 2000). Perhaps not surprisingly some Hui participants drew upon a dominant biomedical discourse of personal responsibility for diabetes. Younger participants were more likely to state that their food and exercise choices contributed to the diagnosis of the disease. But this only tells part of the story. Participants presented a more complex narrative that situated their experience of the disease in a wider political, economic, historical and environmental context. Failing to engage with this narrative and recognise the complexities of Māori engagement with the health system runs the risk of providing health promotion services that are neither in the best interest of the patient, the whānau or the wider community.

These findings have additional implications for interventions that aim to prevent and treat diabetes among Māori. Two examples drawn from the research further illustrate this point. First, there was the commonly stated belief from Māori participants that diabetes is a death sentence, rather than a disease that can be prevented and managed. The strong sense of fatalism contributed to a feeling of grief and frequently denial. One of the strengths of this research was that we prioritised addressing this misconception. Second, poor communication, distrust and cultural insensitivity characterised many Māori interactions with Pakeha dieticians. This finding was significant and provides qualitative evidence of the need for, and importance of, increasing

the number of Māori dietitians. Ministry of Health statistics reveal there are just sixteen Maori dietitians in New Zealand representing just four percent of the national total (“Monitoring” n.d.). As Curtis, Wikaire, Stokes and Reid (2012) have argued, addressing the underrepresentation of indigenous health professionals is recognised internationally as being integral to overcoming indigenous health inequities.

Finally, the research findings substantiate calls for the development of health education programs that address the holistic nature of Maori life, not programs that focus on illnesses like diabetes solely from a deficit or vulnerability perspective. As one of the Hui participants underlined

*Being healthy is not just medical. If you're Māori it's spiritual. It's whaiora. It's everything Māori that we do and we need our whānau on board to be healthy. We need them to be on board and to walk that walk with us. They need to make the changes. That to me is healthy.*

## **51. Why CBPR is a good fit and appropriate for conducting research with Māori**

My study supports the work of those who have found that CBPR is a strong model for working with indigenous populations when designing and implementing type 2 diabetes health initiatives (Boston et al., 1997; Herbert, 1996; Macaulay, 1994; Macaulay et al., 1999; Macaulay et al., 2003; Macaulay et al., 1997). Internationally, CBPR has been demonstrated to be a strong model for work with indigenous populations because it builds on local knowledge and culture, emphasises co-learning and decision making, and priorities local strengths and resources. My results are consistent with these findings. My study shows that the CBPR framework led to the production of a culturally appropriate resource because the partnership model ensured local knowledge was valued, cultural relevance prioritised, and action goals agreed on as a group (see Appendix J supporting letters). For example, the documentary's focus on whānau and making change for the sake of the mokopuna (grandchildren) rather than the individual was directly influenced by the key informants, hui participants and members of the CAB. These findings support the work of Satterfield et al. (2003) who recognised CBPR approaches can help identify social factors like community and family support that can influence health behaviours and ensure cultural relevance. Valuing community expertise and knowledge means prioritising community input. For example, in selecting a fitness objective for the documentary we focused on incremental changes. While Ministry of Health recommendations are for thirty minutes of moderate-intensity physical activity at least five days a week (Ministry of Health, 2015), CAB members considered this to be an unrealistic goal given that hui participants reported participating in little if any physical activity. As a result, incremental changes were promoted.

## **52. Decolonising and indigenising research:**

One of the main challenges of the study was determining how to decolonise the research design and create a culturally appropriate resource. The eight indigenous principles developed by Walters et al. (2009) and applied to this research might prove useful to other non-Māori health researchers. As I have discussed, while there are similarities between CBPR and Kaupapa Māori, there are significant differences. Notably, Kaupapa Māori is Māori initiated, defined and controlled (Walker, 1996). Linda Tuhawai Smith (1999) has suggested that while Pakeha researchers cannot do Kaupapa Māori research they can support Māori Kaupapa. One way is participate in what Cram et al. (2006) term “cooperative independence,” Māori and Pakeha researchers collaborating in separate research areas but working on the same research question. Applying a CBPR model in combination with the eight principles provides another approach for non-Māori researchers to honour indigenous values and protocols. For example, while forming a CAB is a common strategy for CBPR projects, applying the principle of respect led to the CAB being structured as a whanau of interest.” Similarly centring manaakitanga (hospitality) meant that it was not just important to share food, it was as important to share the research findings. Table 4 provides other examples of how these principles can be applied that can serve as a guide for researchers.

Decolonizing research also requires researchers to cede control. Researchers should consider community led Hui as an appropriate method to ensure culturally relevant data. This community-based qualitative approach may be applied to diverse health issues that affect the Māori community. Having community members rather than academics facilitate discussion offers unique advantages. In this instance, CAB members broached the discussion of diabetes with cultural sensitivity and insight. Because of their mana in the community open discussion was ensured. Further, the CAB members understanding of tikanga (protocol) enhanced their interpretation of comments as they recognized and picked up on unspoken cultural nuances.

The importance of the co-analysis of data to ensure cultural relevance was reinforced in this study (Cashman et al., 2008; Israel, Eng, et al., 2005). As outlined in the results chapter, the CAB drew particular attention to interviewee’s discussion of the numerous service delivery barriers preventing Māori from successfully engaging with health services. This was an important observation because Pakeha society often ignores questions about levels of health care and services for Māori (Hodgetts et al., 2004). In contrast, the CAB situated patient noncompliance within a framework of economic, cultural and social barriers that impede people’s ability to prevent or manage type 2 diabetes. Not only did this observation ensure



cultural relevance, the research group also agreed that these findings should be fed back to local primary health organisations and the District Health Board in the hope that this might inform discussion about how to improve engagement with Māori (see Appendix J Cartwright letter).

### **53. CBPR and health communication**

The CBPR model and the research results directly informed the messages conveyed and communicated in the documentary. In doing so the model might prove a fitting one for researchers developing culturally appropriate health promotion materials. The documented process supports literature on health communication that emphasises the need for increased focus on the unique characteristics of racial and ethnic groups in order to address the persistence of health disparities (House & Williams, 2000; Resnicow et al., 2002).

In the introductory chapter I discussed the work of Kreuter et al. (2003) who identified five main categories that health promotion practitioners employ to make materials culturally appropriate. The CBPR model employed in this study reinforces the importance of both constituent involving and sociocultural strategies where a group's "cultural values, beliefs and behaviours are recognised, reinforced, and built upon to provide context and meaning to information and messages about a given health problem or behaviour" (Kreuter et al., 2003, p. 136). The CBPR model produces a culturally relevant design going beyond a "surface structure" of simply attending to appropriate imagery to a "deep structure" that conveys salience (Kreuter et al., 2003; Resnicow et al., 1999; Resnicow et al., 2002). For example, the documentary reinforced the cultural significance of food. The storyline respected and incorporated messaging around traditional meals like boil-ups and the mana (respect) around the social provision of food.

This study makes explicit the process of working in consultation with Māori to develop a resource that reflects Māori beliefs and cultural practices. By detailing the research design, particularly the collaborative process with Māori, and the development of specific communication strategies, my study addressed the identified gap in existing research. None of the major New Zealand diabetes studies have published information detailing how the research design enabled the implementation of communication strategies for type 2 diabetes health promotion initiatives.

The study also clearly identifies the behavioural theory utilised in the creation of the resource. None of the major New Zealand diabetes studies have published information explaining what health behaviour theory was employed, why it was employed, or how it was employed. One of

the strengths of this study is that it demonstrates how social cognitive theory is a good fit for health communication with Māori. While some behavioural theories, including social cognitive theory have been criticised for being Eurocentric and a poor fit for diabetes interventions with ethnic groups (Cochran & Mays, 1993; Oomen, Owen, & Suggs, 1999), as Resnicow et al. (2002) argued, the problem is not with the theory per se but the application. Subsequently social cognitive theory can be adapted for use in different ethnic populations (Bandura, 2001; Bussey & Bandura, 1999; Gilliland et al., 1998). As Resnicow et al. (2002) have cautioned this requires close attention to the surface and deep structure determinants of behaviour in order to successfully translate them into culturally sensitive messages for behaviour change. This argument further reinforces the appropriateness of the CBPR model utilised in this study. Resnicow et al.'s (2002) explanation about what the successful adaptation of social cognitive theory requires is in essence an argument for the CBPR process. Researchers should approach a community from a co-learning perspective rather than a deficit model and recognise that the community has the strengths, wisdom and capability that can be utilised in behaviour change initiatives.

Bandura's (1982) model encompasses thinking about individual agency but also group based determinants of health (collective efficacy). My study supports Resnicow et al.'s (2002) caution that health messages must pay attention to deep structure determinants of behaviour. As previously noted, Pakeha society tends to emphasise individual lifestyle choices and personal responsibility. As the key informants and hui participants made clear, health decisions for Māori must be framed around improvements to the whānau as opposed to the individual. Subsequently, the focus on enhancing collective social cognitive factors was a key focus of the documentary (see Appendix I). Further, social cognitive theory is a good fit for indigenous communities that are tired of being pathologised as a problem. The community clearly identified the need for positive messages and content. Social cognitive theory is culturally appropriate as Bandura's approach is predicated on people responding positively to success (performance mastery, vicarious efficacy and persuasory efficacy). Therefore, the documentary's messaging and visual examples reinforced small achievable changes and highlighted community strengths rather than apportioning blame.

#### **54. Challenges and limitations**

Undertaking CPBR is challenging. The challenges I faced were notably similar to those encountered by Walter et al.'s (2009) work applying indigenous principles, as well as the wider body of CBPR literature.

**Trust and Time:** Building trust takes time. Gaining the trust of community members is one of the most important challenges to overcome. A lack of trust can impede researchers from accessing underrepresented communities, deepening community engagement, and forming a true partnership (Shalowitz et al., 2009). The initial contact and the way relationships are developed in indigenous communities is paramount and process is often more important than outcome (L. Smith, 1999). My research proposal was initially well received because I had a track record of producing collaborative documentaries with other indigenous populations. Second, I wanted to consult on the research design. Third, I was perceived as offering something in return (research reports and a digital resource). Fourth, I spent time getting to know people and building a coalition. Filming did not commence until two years into the research process. This was key because as Baker and Motton (2005) have found it takes time for all parties involved to become familiar with each other's customs and language and feel comfortable asking questions of each other. As they astutely observe, it involves listening rather than talking.

But the time needed to gain trust can also be problematic. Just as others have recognised, time is often the one thing that is in short supply for community partners (Alvarez & Gutiérrez, 2001; Flicker, 2008; Minkler et al., 2002; Stoecker, 2008). Likewise during the three years that passed from proposing the research to launching the documentary, I encountered frustration from some community members about how long the documentary took to create. And bad luck also played a role in extending the time taken to complete the project. Repercussions from the Christchurch earthquakes added to delays. And most important, the earthquakes forced me to relocate to Auckland, away from the community I was working with. This impeded progress due to the importance of Kanohi ki te kanohi (face to face) communication. At the same time, and as discussed in the evaluation, I had to learn to modify my own expectations about time. I learned to recognise that my concept of time structured around the very real dictates of academic deadlines, were not shared by my community partners with their own deadlines and work pressures. This recognition supports the work of Mohammed et al. (2012) who have identified similar tensions between academic and community expectations.

**Balancing academic needs and community interests:** As Springett and Young have observed (2002) evaluation always has a political dimension, “for at the heart of evaluation lies the question of whose values are driving the evaluation and whose standards are being met by the activities being undertaken and assessed or whose standards are being measured against” (Springett and Young, 2002, p. 200). The evaluation criteria outlined in the discussion section demonstrates with pertinent examples a CBPR model that incorporated indigenous principles

into the research design and the messaging of the documentary. As a result the study outlines how to employ CBPR and behavioural theory to create a culturally relevant resource for Māori at risk for type 2 diabetes. The evaluation also demonstrates the methodological rigor of the research through the discussion of credibility, transferability, dependability and conformability.

On reflection though some important questions remain unanswered and looking back I am concerned that my values drove the evaluation rather than the community's values. For example demonstrating methodological rigour speak to academic needs to "prove" my research, but as Bradbury and Reason (2003) have argued, perhaps we need to move beyond the question of validity and start addressing questions like is the work helpful, was it capable of making a difference? To a certain extent there is evidence of this in the production and distribution of two hundred copies of the documentary and letters of support that speak to the strengths of the process. A more formalised process evaluation would have strengthened this evaluation and created space for a community voice and not just my research voice in this evaluation process. By the time I had recognised this it was too late. Some of the CAB members had moved into different organisations and positions and were understandably prioritising new projects. There remain heavy burdens on social service providers given the ongoing repercussions of the Christchurch earthquakes that hit particularly hard in the eastern suburbs that are home to many Māori and social service providers. Notably one of the major governing bodies also announced an extended wind-down of its organisation.

If Bradbury and Reason's (2003) questions are to be answered, it would have been helpful to have a more clearly defined idea of what constitutes success. As Macaulay et al. (2003) have noted, research on what actually defines success in community based health promotion is limited. While I have some anecdotal evidence and letters attesting to its positive reception, the research would have been strengthened by some supporting evaluation from the community. Tracking exactly where the film went has proved to be difficult and is an example of how difficult it was to maintain the proper balance between research protocol and community needs. The documentary was launched nearly three years after the research was initiated and community members, service providers and funders were understandably eager to release the documentary. At the documentary launch copies were informally distributed without a method in place to track distribution. Discussions about how to implement a tracking strategy in the lead up to the launch did not move beyond the informal conversation stage, probably because this reflected my research interests as opposed to the community partners'. This weakness has been identified in previous CBPR studies where sometimes partner priorities to get programmes in

place as rapidly as possible undermines academic interest in demonstrating effectiveness (Doll et al., 2001; Horn et al., 2008; Wallerstein & Duran, 2003).

## **55. Future research**

One of the strengths of the documentary resource is that it translates and disseminates academic research into a useful and accessible resource. I would argue that one of the strengths of producing a documentary through the CBPR process is that it supports the argument that CBPR research can challenge our own academic framing of other people's words (Wallerstein & Duran, 2006), and move beyond what Spivak (1988) calls "ventriloquism" or speaking for community members. However, one of the weaknesses of CBPR is that there is limited evidence to demonstrate whether CBPR processes improve health disparities (Viswanathan et al., 2004; Wallerstein et al., 2008). As part of a post-doctoral study I want to design an evaluation that will look at whether there was a positive change in health literacy among those who watched the film. Was there an increase in knowledge? Was there attitude or behaviour change? One of the ongoing challenges with this type of research is that there is a lack of studies that provide evidence that a specific type of communication or media facilitates behavioural change (Kreuter & McClure, 2004; Shea, Basch, Wechsler, & Lantigua, 1996). As discussed in the literature review, there are a variety of reasons for this. Kreuter and McClure (2004) believe there are few studies isolating the effectiveness of individual channels of communication because it is so difficult to isolate effects. However, there is some evidence for effectiveness that warrants further research. Older research on the use of educational video for non-indigenous low literacy audiences with type 2 diabetes found increased understanding (Lawson et al., 1976; Ward et al., 1984). A meta-analysis conducted in the 1990s found that video was second behind face to face communication in effective messaging (Wilson & Sherrell, 1993). More recent research with video education and those newly diagnosed with type 2 diabetes suggests that video intervention increased diabetes knowledge in the intervention group (Dyson et al., 2010). Significantly, Tuong, Larsen and Armstrong (2012) found evidence that social modelling can facilitate viewer learning. Testing the effectiveness of my research would contribute to this small field of published literature by looking specifically at documentary and health communication with an indigenous population.

## **56. Implications for health planners and managers working in DHBs**

My qualitative research substantiated previous quantitative studies documenting low levels of diabetes knowledge and awareness in the Māori community (De Lore, Hamilton, Brown, & Lunt, 1993; Kirkwood, Simmons, Weblemoe, Voyle, & Richards, 1997). My research data has some additional implications for health planners and managers that can help inform and possibly improve Māori health services. Numerous service delivery barriers continue to prevent Māori from successfully engaging with health services. Māori engagement with health services in Christchurch was characterised as one of distrust, poor communication, negativity and institutional racism. Too often blame is apportioned to those expected to respond rather than a critical examination of the services themselves. These results reinforce previous research that shows a long history of culturally insensitive health services for Māori (Simmons, 1996; Smith & Pearce, 1984).. As noted earlier in the chapter, increasing the number of Maori dieticians and health professionals is key to overcoming indigenous health inequities. (Curtis et al., 2012). To reduce service barriers health planners should consider improved training for health practitioners. Recommendations for improved communication are made in the section below. It is important that Māori health models like Whare Tapa Wha are actively incorporated into mainstream health services. Effective engagement with Māori might require adjustments to appointment times and the way services are structure. For example, key informants recommended not scheduling appointments at the end of the month when money might be an issue for some patients. Longer appointment times should also be considered in order to give medical staff adequate time to establish whakapapa and meeting rooms should be large enough to accommodate extended family support.

When planning future health promotions for the prevention of type 2 diabetes planners should prioritise research that focus on perception and lay understandings of disease and the social and cultural meaning given to diabetes. Employing a CBPR approach can help ensure that health programmes can be responsive to community needs increasing the chances of community support and interventions shaped and determined by the needs of the community.

### **56.1 Implications for health promoters and educators**

My research data has implications for health promoters that can help shape their design of future educational resources. The foundation for successful behaviour change messaging with Māori is a culturally appropriate theoretical framework and a clearly identified health behaviour theory. Furthermore, early and ongoing engagement with key stakeholders is critical. Community driven

initiatives can be more responsive to local concerns and ensure buy in. In depth qualitative interviewing and culturally appropriate processes are important for identifying relevant behavioural determinants. In addition, messages should be culturally tailored and be created in response to community knowledge, experiences, needs or values.

Formative research is a key component to the success of any health promotion campaign. Formative research is necessary in order for health promotion designers to identify relevant behavioural determinants and health behaviour theories (Noar 2006). Campaigns should be based on the target audience's experiences, values and needs in order to understand behaviour and encourage behaviour change. Health promoters should consider CBPR as an appropriate model for health promotions/education because it involves the community at every stage of the research and is therefore responsive to community needs.

One of the most critical conditions for a successful communication intervention is an understanding of the determinants of behaviour in order to influence the behaviour (Whitney and Viswanath, 2004). Successful campaigns should consider the use of in depth interviews and focus groups led by Māori interviewers to solicit an understanding into barriers and facilitators for change. Qualitative research methods can move planning beyond a statistical analysis of a community's health to provide a more nuanced understanding of indigenous experiences. This allows a planner to start where the people are. For example, Ministry of Health recommendations are for thirty minutes of moderate intensity physical activity at least five days a week. However, my research found this was an unrealistic goal given that hui participants reported participating in little if any physical activity. Key informants had advised that they recommend small and incremental steps to their clients. As a result, the documentary messaging focused on incremental changes.

Given the low health literacy of Māori future indigenous focused programmes should consider incorporating documentary video. Digital communication has the potential to be a culturally sensitive form of communication for Māori who have a strong oral storytelling culture as a way to impart knowledge (Bishop, 1996). Documentary video is an appropriate health communication tool as it provides a forum for participants to reflect indigenous cultural beliefs, practises and share their own health narratives.

It is important that health promoters employ behavioural theory in the design of health promotion campaigns. Health behaviour theories are important because they are used to explain and describe why people engage in poor health behaviour and how they can be persuaded to

adopt healthier behaviours. It is important to select a behavioural theory that is suitable for indigenous audiences because some theories can be a poor fit with vulnerable populations (Kennedy & Abbatangelo, 2004). Social cognitive theory is a good fit for Māori health promotions because Bandura (1982) argued that the strength of a group is based in part on people's belief that collectively they have the ability to solve their problems and improve their lives. This is an important distinction as Māori cultural identity is collectivist. Bandura's emphasis on persuasory efficacy maintains an emphasis on positive messaging that avoids blaming and pathologising Māori for poor health outcomes.

Bandura's (1986) observational learning process provides a model to structure communications messages for skills development all of which can be demonstrated through documentary video. Performance mastery, vicarious and persuasive efficacy and personal goal setting can all be influenced by the communications process. Therefore, future research should consider the importance of observational learning through the use of indigenous local role models. Researchers should also consider encouraging self-efficacy by the promotion of positive messages structured around the collective efficacy of a positive narrative from local indigenous health workers.

## **56.2 Implications for health practitioners**

My research data has some useful implications for health providers that can help shape their understanding of Māori experiences with diabetes. By understanding some of the barriers impacting health decisions and reflecting on their own communication styles, medical professionals can improve their interactions with Māori patients. I recap some of the key finding below.

Health professional should recognise that it is common for Māori to have at least one whānau member with the disease. For some Māori diabetes is perceived as a death sentence rather than a disease that can be controlled and managed with the proper care. In most instances this appears to be because patients have directly observed a close family member suffering from diabetes related complications. Therefore, health professionals should anticipate that fear or denial are common reactions to diagnosis and plan accordingly. Whānau support at appointments should be encouraged.

Health professionals should consider their communication styles when conveying information to Māori patients. My research identified a noticeable communications gap between medical



professionals and their Māori clientele. This was attributed to the prevalence of clinical medical language. My research indicates that the Whare Tapa Wha model needs to be better incorporated into discussions of health in order to address the emotional and spiritual needs of Māori patients. Similarly, it is important to recognise that understanding the past is important for engaging Māori. This might include exploring whakawhanaungatanga, or enquiring more broadly about family life before broaching medical information.

Positive and encouraging messages would help address Māori concerns about their interactions with many health professionals. It is important to recognise that personal insult and a undermining of cultural status can be inadvertently implied with negative messaging. Several participants in my study observed that health professionals can nag or belittle a client while at the same time being unaware that the individual has a lot of mana (influence and prestige) within the Māori community.

Poor dietary choices and lack of physical activity need to be considered not just from a biomedical perspective, but also in the context of the established cultural norms in which diabetes is experienced and understood. The loss of cultural traditions can have implications for health. For example, traditional gathering of nutritious kai moana (sea food) was perceived by some research participants as no longer possible due to pollution. Similarly advice about food must consider concepts of cultural hospitality. Large amounts of food are expressions of manaakitanga (hospitality) and mana (prestige). Therefore advice about portion size and food choices should be framed with this understanding in mind.

## **57. Further implications for researchers**

As the discussion in my evaluation chapter made clear, CBPR research data is primarily focused on the generation of local knowledge and producing change in specific targeted communities (Mendenhall et al., 2010). It is important to recognise that communities are unique and these unique features should influence how interventions are developed and implemented. Precisely because the style and delivery of interventions should be shaped and determined by the needs of the community, generalisability will always be compromised. As Tipene-Leach et al. (2013) observed, the intervention principles may be the same but the intervention ‘product’ will be different. I would suggest that while my research findings are not generalisable, the CBPR model I employed might offer some guidance to other researchers considering culturally sensitive research design. What follows are some recommendations to researchers considering working with Māori. Supporting examples are also provided.

This study addressed the need for innovative models and approaches to diabetes education in order to reduce the disparities between Māori and non-Māori disease rates. I have argued that traditional research models are a poor fit with indigenous communities and that a CBPR approach provides a culturally appropriate model for enacting local action-oriented approaches. Kieffer et al. (2004) have argued that intervention strategies designed following CBPR principles will reflect the cultural values, behavioural preferences, and environmental context of the participating community.

There were several examples of how my CBPR process reflected cultural values, most specifically tikanga (customs) that might prove useful to researchers working with Māori. One of the ways I prioritised indigenous knowledge and cultural protocols was basing the approach to the CAB on the concept of whanaungatanga (togetherness). Following Bishop's (1998) recommendations, the CAB was structured as an extended family, what Bishop calls a 'whanau of interest.' This requires researchers to function as co-learners. By eschewing the 'expert' role and hierarchical research model that distinguishes between researcher and the researched, community support can be garnered and sustained. Researchers should also approach Kaumatua for support and guidance at the inception of a research project and be guided by them throughout the research process.

The CBPR process also reflected the behavioural preferences and environmental context of the community which led to the creation of an appropriate and relevant resource. Researchers should consider qualitative research design in order to ascertain Māori perceptions and understanding of disease. While statistical data can demonstrate that diabetes is a severe problem in the community, in depth interviews and hui can reveal why. Participants in my study described often complex historical (loss of traditional practices like fishing from unpolluted rivers), structural (service barriers that prevent engagement) economic (cost of healthy food/lack of time) and social reasons (manaakitanga) for poor health and the high rates of diabetes in the Māori community. In addition to promoting lifestyle changes, community based qualitative approaches can assist researchers in identifying social factors like community and family support that can influence health behaviours. In the case of my research, community members identified strong positive motivations for change—being there for grandchildren and the motivating idea of whānau leading whānau. Understanding behavioural preferences is a prerequisite for meaningful and culturally appropriate interventions. Researchers need to understand the target audience's experiences, values and needs in order to understand behaviour and encourage behaviour change. Qualitative methods like key informant interviews and focus groups provide an opportunity to

gather rich data about historical, social and environmental barriers and community norms, values and beliefs. A qualitative approach might also prove useful for work with other ethnic groups in New Zealand with high rates of diabetes, for example the Pasifika and Asian populations.

My research also made clear that a schism remains between a dominant Western biomedical understanding and explanation of disease and a more holistic understanding embodied in Māori models of health like Whare Tapa Wha. This makes the CBPR approach particularly pertinent for researchers, especially as other ethnic groups have holistic models and understandings of health (for example, in Pacific Island culture the Fonofale house model incorporates an understanding of physical, spiritual and mental elements). CBPR is a useful model for guiding researchers on respecting, recognising and incorporating indigenous health models into academic research. CBPR's epistemology challenges the idea of objectivity and incorporates multiple ways of seeing the world. As Fletcher (2003) noted, CBPR is an important tool for researchers working with indigenous populations because it acknowledges different ways of knowing and gives equal weight to scientific and cultural expressions of knowledge.

Finally, I would recommend that researchers adopt Walters et al.'s (2009) eight indigenist principles in their research design. These principles also serve as a good benchmark by which to assess the cultural appropriateness of research with indigenous communities. For example, the principle of resilience and research design that acknowledge the community's strengths can guide researchers away from a deficit model of health to one that places primacy on communicating positive stories from the community. Adopting a holistic model of health can reframe health promotion away from positioning indigenous people as a problem to highlighting community strengths and resilience.

In conclusion, culturally appropriate diabetes education must remain a priority. If left unchecked diabetes related costs have the potential to overwhelm the New Zealand health system. The cultural, social and economic stakes are high. Higher mortality rates among Māori deprive whānau, hapu and iwi of kinship and leadership. The government, DHBs, researchers and health promoters must do a better job of supporting, creating and reporting on culturally appropriate communication. It is imperative that researchers continue to utilise CBPR processes and report on the use of behavioural theory. We need to make explicit the research process followed and strategies employed to engage the community. And we need to report on the shortcomings as well as the successes of this approach. As the research has demonstrated, CBPR provides a strong and model for working with Māori. CBPR could and should be applied to future research with the goal of reducing the gap between Māori and non-Māori disease rates.

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## Appendix A. Ethics Consent



Upper South A Regional Ethics Committee  
c/- Ministry of Health  
Montgomery Watson Building  
6 Hazeldean Road  
Christchurch  
Phone: (03) 974 2304  
Email: [uppersoutha\\_ethicscommittee@moh.govt.nz](mailto:uppersoutha_ethicscommittee@moh.govt.nz)

27 February 2012

Ms Alison Farmer  
Health Science Centre  
Room 108, Level 1, Waimairi Building  
University of Canterbury  
P O Box 4800 Christchurch

Dear Ms Alison Farmer

**Ethics ref:** URA/10/11/074 (please quote in all correspondence)  
**Study title:** A community based participatory approach to diabetes education for Christchurch Maori  
**Investigators:** Ms Alison Farmer

Thank you for the progress report for the above study, which was considered by the Chairperson of the Upper South A Regional Ethics Committee.

Ethical approval is confirmed for a further 12 months from the report due date. We look forward to receiving another report from you in December 2012.

Yours sincerely

**Alieke Dierckx**  
Administrator  
Upper South A Regional Ethics Committee  
[Uppersoutha\\_ethicscommittee@moh.govt.nz](mailto:Uppersoutha_ethicscommittee@moh.govt.nz)

08 July 2014

MS ALISON FARMER  
80 SCENIC DRIVE  
TITIRANGI  
AUCKLAND 0614

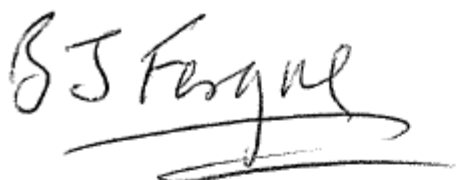
Dear MS FARMER

Re:	Ethics ref:	URA/10/11/074/AM02
	Study title:	A community based participatory approach to diabetes education for Christchurch Maori

I am pleased to advise that this amendment has been approved by the Northern A Health and Disability Ethics Committee. This decision was made through the HDEC Expedited Review pathway.

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,



Dr Brian Fergus  
Chairperson  
Northern A Health and Disability Ethics Committee

Encl: appendix A: documents submitted  
appendix B: statement of compliance and list of members

## Appendix A

### Documents submitted and approved

Document	Version	Date	
Post Approval Form	02	25 June 2014	

## Appendix B

### Statement of compliance and list of members

#### Statement of compliance

The Northern A Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008714) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

#### List of members

Name	Category	Appointed	Term Expires
Dr Brian Fergus	Lay (consumer/community perspectives)	01/07/2012	01/07/2015
Dr Karen Bartholomew	Non-lay (intervention studies)	01/07/2013	01/07/2016
Ms Susan Buckland	Lay (consumer/community perspectives)	01/07/2012	01/07/2015
Ms Shamim Chagani	Non-lay (health/disability service provision)	01/07/2012	01/07/2015
Dr Christine Crooks	Non-lay (intervention studies)	01/07/2013	01/07/2015
Mr Kerry Hiini	Lay (consumer/community perspectives)	01/07/2012	01/07/2015
Ms Michele Stanton	Lay (the law)	01/07/2012	01/07/2015

<http://www.ethics.health.govt.nz>

## Appendix B. Information Sheet

### Appendix B. Information Sheet

#### Health Sciences Centre

Associate Professor Ray Kirk  
Director, Health Sciences Centre  
Director, Health Services Assessment Collaboration (HSAC)  
Tel: +64 3 364 2987 ext. 3108, Fax: +64 3 364 3318,  
Email: ray.kirk@canterbury.ac.nz



Researcher: Alison Farmer  
PhD Candidate  
Health Science Centre  
Room: 108, Level 1, Waimairi Building  
University of Canterbury  
Email: alison.farmer@pg.canterbury.ac.nz  
Phone: 0210517793

#### INFORMATION SHEET (Key Informants)

##### **A Community Based Approach to Diabetes Education for Christchurch Maori**

You are invited to take part in a community based research project. This study aims to develop a video that can be used as educational resource for Christchurch adult Maori at risk for/with Type 2 diabetes.

##### **About the Study:**

In New Zealand, diabetes is almost three times more common in Maori than non-Maori. Maori are diagnosed younger and are two to three times more likely to develop complications such as eye disease, kidney failure, strokes and heart disease.

Several studies of Maori Health identify the need for new approaches to diabetes education in order to reduce the gap between Maori and non-Maori disease rates. A significant barrier is a lack of knowledge and access to health information.

Research suggests that the reported low level of diabetes knowledge in the Maori community is due to a lack of culturally appropriate media. There is a clear need for an effective community based model that reflects Maori beliefs and cultural practices. There are few audio visual materials focusing on Maori health and a lack of academic studies on video communication and diabetes education..

Better communication efforts are needed in the prevention of diabetes in Maori communities. This study will employ a Community Based Participatory Research approach to develop an effective video for adult Christchurch Maori at risk for/with Type 2 Diabetes.

##### **What is Community Based Participatory Research? (CBPR)**

It's a research model that actively involves community members and local organizations at every stage of the research process. Alison Farmer has successfully used this model with ethnic groups in the United States to produce public health videos



The research approach is rooted in a commitment to share power with and engage community partners in the research process. CBPR

- Builds on strengths and resources within the community, individuals, networks and organizations
- Improves the quality of research by engaging local knowledge and local theory based on the actual experience of the people involved
- Relies on participants recommending strategies for improving health issues in ways that are directly relevant to their lived experiences

The research will be undertaken in several stages. From January 2011 —April 2012 the following will be completed.

1. Interviews with health and social service providers that work on the prevention and management of diabetes
2. Hui with Christchurch based Maori about their beliefs and attitudes related to diabetes
3. Interviews with Christchurch based Maori about their media preferences
4. Hui with Christchurch based Maori and health and social service providers to gather opinions and advice about the video production.

You are invited to participate in this study because you have experience in one or both of the following

- (a) The prevention and management of diabetes and/or
- (b) Maori public health or health promotion

Your participation is entirely voluntary (your choice). You do not have to take part in this study. Please take up to seven days to decide whether to take part. If you do agree to take part in the study, you are free to withdraw from the study at any time, without having to give a reason to the researcher or any participating organization

If you agree, you will be asked to participate in a one-on-one interview with the Alison Farmer to

- Discuss local perceptions and understanding of Type 2 diabetes, strategies for health behaviour change and the potential audience for the video
- Make recommendations for the wording of a focus group guide
- Make recommendations for focus group recruitment

The interview will take place at a location of your choice. It will last approximately 60 minutes. Each interview will be audio-taped and transcribed. All personal identifiers will be removed to maintain confidentiality and to encourage open discussion. Tapes and transcripts will be stored in a locked cabinet at the Health Sciences Centre at the University of Canterbury. Alison Farmer and her immediate supervisors will be the only researchers with access to the study documents.

After the interview is complete you will be offered the opportunity to review your personal transcript for accuracy, validity and additional comments. You will be invited to make recommendations for the next stage of data collection and asked to offer additional feedback on the design and wording of the focus group guide.

You will be offered the choice of receiving a mailed hard copy and/or an emailed copy of the transcripts, stage summaries and the revised focus group guides. The researcher will request verbal (via telephone conference) or written (email/mailed) feedback within a four week period.

After the initial interview, Alison Farmer will also ask for your recommendations for the wording of a focus group guide. This can be submitted verbally (via telephone conference) or through written (email/mailed) feedback

## General

If you need an interpreter one can be provided.

You do not have to answer all the questions, and you may stop the interview at any time.

No material that could personally identify you will be used in any reports on this study.

Transcripts and tapes will be stored in a locked filing cabinet at the Health Sciences Centre, University of Canterbury. Only the principle investigator will have access to the study documents. If at any stage an outside service is engaged to transcribe any of the interview data they will be required to sign a confidentiality agreement as a condition of hire. The raw data will be securely stored for a duration of 10 years. The data will then be destroyed.

You will be provided with a copy of the published results and with a copy of the final video. If requested by you, Alison Farmer will also present the results to the participants' employing organization. The PhD is a public document and will be available via the UC library database

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

This study has received ethical approval from the Upper South A Ethics Committee, ethics reference number URA 10/11/074

Please feel free to contact the researcher or her immediate supervisor if you have any questions about this study.

Room: 201, Level 2, Waimairi Building

Phone: + 64 3 366 7001 ext 7403

Fax: + 64 3 364 3318

[jeffrey.gage@canterbury.ac.nz](mailto:jeffrey.gage@canterbury.ac.nz)

## Appendix C. Consent Form

### Appendix C. Consent Form

Health Sciences Centre

Associate Professor Ray Kirk  
Director, Health Sciences Centre  
Director, Health Services Assessment Collaboration (HSAC)  
Tel: +64 3 364 238 / ext. 3108, Fax: +64 3 364 3318,  
Email: ray.kirk@canterbury.ac.nz



### A Community Based Approach to Diabetes Education for Christchurch Maori

#### Consent Form

English	I wish to have an interpreter	Yes	No
Deaf	I wish to have a NZ sign language interpreter	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhaka Māori/kaiwhaka pakeha korero	Ae	Kao

I have read and I understand the information sheet dated 01/12/10 for volunteers taking part in the study designed to create a video for Christchurch Adult Maori at risk for/with Type 2 diabetes. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my future health care/continuing health care.

I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

I am aware that during the group discussion it is possible that personal or sensitive information may be disclosed. I agree to keep this information strictly confidential, but I understand that no guarantee can be given that information about me will be kept private

I have had time to consider whether to take part in the study.

I know who to contact if I have any questions about the study

I consent to my interview being audiotaped/videotaped	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
I wish to receive a copy of the results.	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
I would like the researcher to discuss the outcomes of the study with me	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

I (full name) hereby consent to take part in this study.

Date:

Signature:

Name of researcher: Alison Farmer

Researcher contact: 0210517793

Project explained by: Alison Farmer

Project role: Lead researcher

Date:

Signature:

## Appendix D. Key Informant Interview Guide

### INTERVIEW GUIDE Key informants (KI):

**Starting the interview:** Describe project and how I will conduct the research—cover confidentiality, anonymity and other pragmatic issues (recording)

**1. Demographic details:** Open interview by getting background on the KI—the specific work they do re. Diabetes—how long have they worked in this field—typical clientele etc

*Q1. Tell me about your work with diabetes patients.*

*Q2. How much of a problem do you think type 2 diabetes is in the community you serve?*

Probe: why do you think this is?

Explore **structural and lifestyle** explanations (Structural explanations for poor health—education, work/income, community norms and/or lifestyle explanation—idea of personal choice and responsibility.

**Community Knowledge:** Explain that I want to understand something about their general perception of the current level of knowledge and awareness of Type 2 diabetes (in relation to their clients)

*Q3. If you were to ask a client/patient what is diabetes? What is the typical response you'd get?*

Probe: are there differences based on age, gender, etc?

Probe: For those that know: Is it a westernised/ medical understanding of health with an emphasis on the physical? Or is it a Maori understanding of health that is more holistic?

*Q4. Beliefs: If you were to ask a client what causes diabetes what explanations might you receive?*

Probe: structural and lifestyle explanations

*Q5. Beliefs: If you were to ask a client what prevents diabetes what explanations might you receive?*

Probe: Again explore incorporation of Maori view of health—that knowledge, beliefs and values —are cultural and might help define behaviours?

*Q6. If you were to ask a client to explain some symptoms or complications from diabetes what sorts of answers might you hear?*

*How do you explain diabetes to them? Its causes, symptoms, complications?*



Probe: Why do they explain it this way—based on previous experiences?

Probe: Do they incorporate a Maori model of health—why/why not?

***Q7. How would you describe the current level of understanding of diabetes in the community?***

How and why have they reached that conclusion?

***Q8. What do you think the difference is between those who make changes and those that don't?***

Impt: Explore barriers and facilitators with healthy eating/physical activity

***Q9. What educational resources are currently available? What resources do you use?***

Explore how useful they are to them/to clients. How wide is the range, where are the gaps/needs?

Explore where people get their health information from

***Q10. In your opinion/assessment, what is the biggest problem you face when educating the community about diabetes?***

**3. Target Audience:** Ask for KIs help with Identification of the **target population** for the video resource/intervention

***Q11. Based on your experience/in your opinion who is the ideal audience for a documentary focusing on diabetes education?***

Probe: WHY? What are the reasons for identifying this audience?

***Q12. Who is most likely to be influenced/ change?***

## Appendix E. Code Book

J

### **Diabetes: Prevalence and Impact of**

Diabetes-problem	Prevalence in community served
Diabetes-Family Experience	Diabetes as heredity
Diabetes-Fear of	Fear of diagnosis-belief it's a death sentence
Diabetes-reaction to diagnosis	How patients react to news

### **Diabetes: Causes of**

Diabetes -clients awareness of cause	Client awareness of cause-heredity, weight, food, exercise
Diabetes-client misconceptions of cause	Belief in too much sugar

### **Diabetes Care and Service Delivery**

Diabetes-Management-Health Workers	Attitudes of health workers to patients
Diabetes-Services-Barriers	Any circumstance preventing Maori from receiving appropriate care
Diabetes Management-patients	Attitudes of patients to health workers-how they manage advice
Diabetes patients-advice	What advice health workers typically give about managing T2D
Diabetes Services-Holistic	Examples of how care is/should be delivered holistically
Diabetes Services-Solutions	Examples of what works with Maori patients/service delivery

### **Diabetes-Education**

Diabetes-Education	How education is currently delivered by health workers
Diabetes-Education-Media-future	How education could be improved/should be delivered
Diabetes-Education-Media-opinions of	Health workers opinion of existing health promotion resources
Diabetes-Education-Media-use of	Health workers use of existing health promotion resources

### **Barriers to Healthy Eating/Physical Activity**

Barriers-Cultural	Culturally specific barriers to maintaining good health
Barriers-Cultural-Food	Expectations about provision of food at social gatherings
Barriers-Denial	Denial/failure to acknowledge diagnosis
Barriers-Earthquake	Barriers to maintaining good health caused by earthquake
Barriers-Economic	Financial constraints on maintaining good health
Barriers-Economic-Food	Financial constraints impacting the purchase of healthy food
Barriers-Education	Lack of knowledge about causes and/or management of T2D
Barriers-Exercise	Constraints on participating in physical activity
Barriers-poor food choices	Consumption of unhealthy foods/takeaway
Barriers-Racism	Racist attitudes and beliefs of Non-Maori
Barriers-whanau	Whanau members undermining or resisting a family member's efforts to change
Barriers-Mental Health	Impact of mental health on ability to change
Barriers-Social Marketing	Impact of social marketing on individual's health
Barriers-Shame	Impact of shame or embarrassment relating to weight

## **Facilitators**

**Solutions-Cultural-Food**

Healthy ways to include cultural traditions

**Solutions-Economic**

Practical ways to improve finances/financial management

**Solutions-Economic-Food**

Affordable improvements to purchase/cooking of food

**Solutions-Exercise**

Easy and affordable ways to incorporate physical activity

**Solutions-Food & Diet**

Advice about how to make food recommendations

**Solutions-Kaumatua-elders led**

Kaumatua support for change

**Solutions-whanau support**

Ways to encourage whanau to support change to food/physical activity

**Solutions-cultural**

Culturally specific approaches tailored for Maori

## Appendix F. Draft of hui questions with feedback and revisions

### Participants' knowledge and understanding of diabetes

- Do you have friends or family diagnosed with diabetes? What has that experience been like?
- OR for those already diagnosed: Since you've been diagnosed with diabetes what has the experience been like?
- What is your understanding of diabetes? What does it mean to you?
- What might cause diabetes?
- Are you aware of any problems someone might experience if they get diabetes?
- OR for those already diagnosed: What problems have you experienced since being diagnosed with diabetes?
- Are you aware of any ways to prevent diabetes?
- OR for those already diagnosed: Were you aware of any ways to prevent diabetes?
- Are you aware of any symptoms?
- OR for those already diagnosed: Were you aware of any ways to symptoms before being diagnosed with diabetes?
- How likely do you think you are personally are to develop diabetes?
- In your opinion, how serious a health risk is diabetes?

**Comment [S1]:** *I always ask them have they got any stories or anything they want to say about diabetes that they've heard or that's upset them in the past, anything, I just start with that.*

**My note:** Might be a good way to get discussion going in a hui setting. Discuss with advisory group at October meeting

**Comment [S2]:** *Put something about associated fears with what does it mean to you? Is there anything that you are afraid of? There may be some fear because they may know someone who has had their leg chopped off. But I think the way you've worded it makes it unlike a quiz because you've asked how was it for you? What does it mean to you? What was your experience? You are trying to find out what they know so I think it's pretty good.*

**Comment [S3]:** **My note:** FEAR This is an impt qu given that FEAR of diabetes and/or a diagnosis of is an over riding theme that has emerged from these interviews.

**Comment [S4]:** *I like the question, are you aware of any ways to prevent diabetes? because that's what we are really wanting, we want that awareness and we constantly try to raise it that awareness through weight loss and exercise. And if I say to them what you do now will impact on what happens all these years down the road, but I don't get the opportunity to say that.*

*Or for those already diagnosed: Were you aware of any ways to prevent diabetes? It's really hard for us because we work in both areas but the majority of our work is obviously in the already diagnosed so we are asking so what could you have done?, and we are kind of like working backwards but not getting anywhere forwards so its like how do we get that message to the ones that aren't currently diagnosed and so I really like that questions*

*They will all be able to answer that were you aware of ways to prevent ? They will be now aware but they weren't then.*

**Comment [S5]:** *I especially like the questions like are you aware of any symptoms or were you aware of any symptoms before you were diagnosed with diabetes, because I think that's one of the things that, that people do struggle with is that they feel fine, here we want to give them this medication that might give them some side effects or you know do this, that or the other and it's a bit like trying to treat hypertension when somebody feels fine even though there blood pressure's sky high and trying to sort of frame that risk for them to say you know inevitably you're saying this is a potentially life long course of treatment that you're setting out on now it's not just take this for 10 days and [you'll feel better sort of thing*



**What is the best way to discuss people's attitudes towards diet and exercise?**

- How do you feel about healthy eating// exercise?
- Do you ever discuss healthy eating// exercise with friends and whanau? What do you talk about?
- What are some of the reasons you might change your diet or exercise? (What would encourage you to change?)
- What are some of the things that might put you off changing your diet or exercise? (What would discourage you to change?)

**Comment [S6]:** Comments expressed by KIs that they should be there for HUI and to be aware of sensitivity of questions

*Because their mana is on the line when you start doing that sort of thing and their ability to provide and it's a pride, now I'm just admitting that I can't provide for my own whanau and so it's almost like.. so sometimes you get a retaliative response because its almost like a challenge to their mana. They already know what they can't achieve and they don't need to be reminded and so it's really hard unless you know these things.*

Another comment  
*there may be a role for someone to facilitate or someone with a bit of mana even by introduction and association it's like saying well if they are introducing you it's okay by default with them therefore this Alison must be okay.*

**Comment [S7]:** Recommendation made to separate diet and exercise questions into two discrete categories.

*Also, So if you say to somebody **how do you feel about healthy eating and exercise?** they don't know what exercise is.*

**Comment [S8]:** Add a new question: **What is exercise to you?**

*But my question I'd like to look into deep is what do you think exercise is? To you what is exercise? Rather than say how do you feel about exercise?*

*it's the exercise that seems to be the biggest downfall. So what is exercise to you? What does that mean? And some will say I'm not going to the gym. and I'm not doing this. So when you have an understanding and you share an understanding of what exercise is to them you can kind of start well exercise to me is...*

*Well that's the thing because I don't think they know either. So if you say to somebody **how do you feel about healthy eating and exercise?** they don't know what exercise is. They don't have an understanding of what exercise is. So I think that's a question that we could ask them, what is exercise to you?*

*I think the question we should ask is just what is exercise? What is it? Because I don't even know. All I know is its looking after your tingana and your well being and your physical. But is it that? I'd like to hear what they perceive it to be. What is exercise? Just that straight*

- Does the media have any influence on your opinion or decision making when it comes to diet or exercise

**Comment [S9]:** *I think the role of the family is a good thing because you just come out and ask the people what role do you take? My husband does the cooking and I do the shopping you know? Not everyone in Christchurch is affiliated to a marae but if they are you will probably find that in Rapaki rather than in Christchurch itself. However, they might speak about their own marae up north. So that is still a good question. When you get people talking about who they are, where they come from and where they belong it's a good dialect and way to lead them to what you want to know because it will also bring about oh I've got cousins and they've got diabetes and they all smoke and I don't want to be like them and blah blah blah...The whanau leads on to the bigger picture and who in the whanau has got diabetes*

## **Revisions to Hui Questions**

As noted above the Hui questions will be modified to explore and extend the themes that emerged from the individual interviews.

### **Knowledge and Understanding**

- All of the key informants said their patients/clients believe diabetes is caused by eating too much sugar and that there is a low level of understanding re. the role of food and exercise. These observations need to be confirmed. **If accurate, a potential message for our DVD might be addressing the misconception about what diabetes is and what causes diabetes.**
- Key informants suggested that knowledge about how to prevent diabetes (from getting worse) only comes when the consequences of failing to manage diabetes are taking a physical toll. **Let's explore this idea in the Hui with the aim of gaining some insights that might inform the DVD content. Why exactly don't patients make the changes earlier? Is there a link to fear/denial identified by the key informants?**
- Key informants overwhelmingly stated that most of their patients see diabetes as a death sentence rather than a disease that can be controlled and managed with the proper care. In some instances this appears to be because patients have directly observed a close family member suffering from diabetes related complications. **This is an important theme to explore in the Hui. How have direct observations of family members impacted beliefs? The misconception that diabetes is a death sentence might become a key belief to target in the DVD.**

### **Beliefs: Attitudes and Practices Related to Diet and Exercise**

- Key informants discussed several barriers that might prevent their Maori clients from changing their diet and/or exercising. **Explore in the Hui**
- Key informants identified several service delivery barriers that might impact on Maori being willing to engage with medical services. **An important area to explore in the Hui.**

**The next draft of the Hui questions follows. Please provide your feedback and revisions**

**Participants' knowledge and understanding of diabetes**

Do you have friends or family diagnosed with diabetes? What has that experience been like?  
Are there any stories that you might be willing to share?

OR for those already diagnosed: Since you've been diagnosed with diabetes what has the experience been like? Are there any stories that you might be willing to share?

What is your understanding of diabetes? What does it mean to you?

- Is there anything that you are afraid of? (**PROBE: Idea of diabetes as a death sentence. Also fear of insulin and needles**)

What do you think might cause diabetes?

- **PROBE: Idea that sugar causes diabetes. See if any linkage is made with lifestyle causes-kai and exercise)**

Are you aware of any problems someone might experience if they get diabetes?

OR for those already diagnosed: What problems have you experienced since being diagnosed with diabetes?

- **PROBE: how are they dealing/not dealing with them? Lessons learned?**

Are you aware of any ways to prevent diabetes?

- **See if any linkage is made with lifestyle causes-kai and exercise)**

OR for those already diagnosed: Were you aware of any ways to prevent diabetes?

- **PROBE: Did you make changes once diagnosed? Why/why not?**

Are you aware of any symptoms?

OR for those already diagnosed: Were you aware of any ways to symptoms before being diagnosed with diabetes?

How likely do you think you are/did you think you were personally to develop diabetes?

## **Personal Beliefs about Nutrition and Exercise**

What does "being healthy" mean to you?

What is exercise to you?

What kinds of physical activity do you regularly engage in?

WHY do you do it?

What are some of the reasons you might engage in physical activity?

### **PROBE**

- Lack of support- childcare etc.
- Safety concerns- streets not safe
- Lack of motivation-
- Lack of confidence/low self-esteem **\*\* (link to self-efficacy)**
- Time-too busy to exercise
- Perceived Cost/Expense-
- Transportation- difficult to travel to venues that run sporting activities
- Existing health problems

What are some of the reasons you might?

How important is physical activity to you?

How important do you think physical activity/exercise is to your friends and whanau? Do you ever discuss it with them? **\*\* (Link to perception of what others think/do)**

Do the media have any influence on your opinion when it comes to exercise/physical activity?

What does "healthy eating" mean to you?

How easy is it for you to eat healthy?

### **PROBE ANTICIPATED BARRIERS**

- Cost
- Transportation-access to fresh food
- Time—too busy to cook/convenience food
- Family-kids don't like change in diet

What are some of the reasons why you might change your eating habits?

Can you tell me about a time when you changed what you were eating?

- Why did you do that?
- What happened? (positive/negative experience)

How important do you think healthy eating is to your friends and whanau? Do you ever discuss with them? \*\* **(Link to perception of what others think/do)**

Does the media have any influence on your opinion when it comes to healthy eating?

## Appendix G. Hui Information Sheet

### Appendix G Hui Information Sheet

Health Sciences Centre

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Director, Health Services Assessment Collaboration (HSAC)  
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Email: ray.kirk@canterbury.ac.nz



Researcher: Alison Farmer  
PhD Candidate  
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Room: 108, Level 1, Waimairi Building  
University of Canterbury  
Email: alison.farmer@pg.canterbury.ac.nz  
Phone: 0210517793

#### INFORMATION SHEET (Hui)

##### **A Community Based Approach to Diabetes Education for Christchurch Maori**

You are invited to take part in a community based research project. This study aims to develop a DVD that can be used as educational resource for Christchurch adult Maori at risk for Type 2 diabetes.

You are invited to participate in this study because we want to know what community members currently understand about diabetes and what stories you would like to see portrayed in the DVD.

Your participation is entirely voluntary (your choice). You do not have to take part in this study. Please take up to seven days to decide whether to take part. If you do agree to take part in the study, you are free to withdraw from the study at any time, without having to give a reason to the researcher or any participating organization

If you agree, you will be asked to participate in a hui to discuss your

- Understanding of Type 2 diabetes,
- Beliefs and practices related to diet
- Beliefs and practices related to physical activity

The Hui will be video-taped so that the researcher has an accurate record of the conversation. Your name or photographic likeness will never be used or published in the research. All personal identifiers will be removed to maintain confidentiality and to encourage open discussion. Tapes will be stored in a locked cabinet. Alison Farmer and her immediate supervisors will be the only researchers with access to the tapes or study documents.

The information obtained during the group discussion will be regarded as confidential and is to remain within the group setting. While every effort will be made to maintain confidentiality, it cannot be guaranteed.

At the end of the hui you will be asked to feedback on the discussion process. Both interviewer and participants will summarize what they believe to be the key ideas to emerge from the discussion.



After the hui, the researcher will analyze the data to identify key themes. You will be invited to review, confirm and revise the findings. You will be offered the choice of receiving a mailed hard copy and/or an emailed copy of the key themes document. The researcher will request verbal (via telephone conference) or written (email/mailed) feedback within a four week period.

At this feedback stage you will be invited to participate in the next stage of the research. This will be an individual interview to discuss your opinions about what you would/would not like to see in a video. An information sheet explaining the process will be made available at that time.

## **General**

Kai and drinks will be provided during the focus groups. A petrol voucher as koha will be provided to cover travel costs to the focus group destination.

If you need an interpreter one can be provided.

You do not have to answer all the questions, and you may stop the interview at any time.

No material that could personally identify you will be used in any reports on this study.

Transcripts and tapes will be stored in a locked filing cabinet. Only the principle investigator and her immediate supervisors will have access to the study documents. If at any stage an outside service is engaged to transcribe any of the interview data they will be required to sign a confidentiality agreement as a condition of hire. The raw data will be securely stored for a duration of 10 years. The data will then be destroyed.

You will be provided with a copy of the published results and with a copy of the final video. The PhD is a public document and will be available via the UC library database

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

This study has received ethical approval from the Upper South A Regional Ethics Committee, ethics reference number URA/10/11/074

Please feel free to contact the researcher or her immediate supervisor if you have any questions about this study.

Room: 201, Level 2, Waimairi Building

Phone: + 64 3 366 7001 ext 7403

Fax: + 64 3 364 3318

[jeffrey.gage@canterbury.ac.nz](mailto:jeffrey.gage@canterbury.ac.nz)

## **About the Study:**

In New Zealand, diabetes is almost three times more common in Maori than non-Maori. Maori are diagnosed younger and are two to three times more likely to develop complications such as eye disease, kidney failure, strokes and heart disease.

A Community Based Approach to Diabetes Education for Christchurch Maori (version 4 created on 01/12/2010)  
University of Canterbury Private Bag 4800, Christchurch 8020, New Zealand. [www.canterbury.ac.nz](http://www.canterbury.ac.nz)



Several studies of Maori Health identify the need for new approaches to diabetes education in order to reduce the gap between Maori and non-Maori disease rates. A significant barrier is a lack of knowledge and access to health information.

Research suggests that the reported low level of diabetes knowledge in the Maori community is due to a lack of culturally appropriate media. There is a clear need for an effective community based model that reflects Maori beliefs and cultural practices. There are few audio visual materials focusing on Maori health and a lack of academic studies on video communication and diabetes education.

Better communication efforts are needed in the prevention of diabetes in Maori communities. This study will employ a Community Based Participatory Research approach to develop an effective video for adult Christchurch Maori at risk for/with Type 2 Diabetes.

#### **What is Community Based Participatory Research? (CBPR)**

It's a research model that actively involves community members and local organizations at every stage of the research process. Alison Farmer has successfully used this model with ethnic groups in the United States to produce public health videos.

The research approach is rooted in a commitment to share power with and engage community partners in the research process. CBPR

- Builds on strengths and resources within the community, individuals, networks and organizations
- Improves the quality of research by engaging local knowledge and local theory based on the actual experience of the people involved
- Relies on participants recommending strategies for improving health issues in ways that are directly relevant to their lived experiences

The research will be undertaken in several stages. From January 2011 —April 2012 the following will be completed.

1. Interviews with health and social service providers that work on the prevention and management of diabetes
2. Hui with Christchurch based Maori about their beliefs and attitudes related to diabetes
3. Interviews with Christchurch based Maori about their media preferences
4. Hui with Christchurch based Maori and health and social service providers to gather opinions and advice about the video production.

## Appendix H. Hui Summary Tables

### SUMMARY: DISCUSSION TOPIC ONE

Knowledge of Diabetes as a Disease	Experience Of Diabetes
<p><b>Cause</b></p> <p>-- Hui participants unable to identify cause</p> <p>--Belief its caused by too much sugar (Key Informants also reported)</p> <p><b>Symptoms</b></p> <p>--Hui participants (both with/without diabetes) unable to identify symptoms</p> <p>--Possible to confuse symptoms with signs of aging (men w/diabetes)</p> <p><b>Prevention</b></p> <p>--As KIs suggested knowledge only comes when a patient's diabetes is at an advanced stage and consequences are taking toll. They've been educated since diagnosis but many still failing to act</p> <p>--Men without diabetes group identified exercise as a preventative measure</p> <p>While most Hui participants have direct family experience with diabetes, this does not translate into an understanding of causes, symptoms or prevention.</p> <p>Research reinforces the observations previously made by KIs in the one-on-one interviews. It also substantiates previous academic research documenting low levels of diabetes knowledge and awareness in the Maori community.</p> <p>Possible Communication Message: Address misconception /lack of knowledge about what causes diabetes -identify some symptoms (but avoid conveying message in clinical terms—see Topic 3 findings)</p>	<p><b>Diabetes as a Whanau Experience</b></p> <p>--Majority of Hui participants have whanau with diabetes</p> <p>Those with diabetes discussed their own diagnosis as expected in light on their family history; it was perceived as a hereditary condition. Those without diabetes didn't express the same expectation that they would get diabetes although their family experiences were often quite similar. However, It can't be determined whether this is an actual difference or rather an after-the-fact way for people with diabetes to rationalise the diagnosis.</p> <p><b>Fear</b></p> <p>--Women without diabetes expressed fear husbands were vulnerable</p> <p><b>Fear It's a Death Sentence</b></p> <p>--rather than a disease that can be controlled and managed (see KI Interviews)</p> <p><b>Fear of Needles/Insulin</b></p> <p>--Women with diabetes (see also KI interviews)</p> <p><b>Fear of Losing Physical Fitness (becoming vulnerable?)</b></p> <p>--Men with Diabetes-no longer bullet proof</p> <p><b>Denial</b></p> <p>--Men and women with diabetes (see also KI interviews)</p> <p>--as a coping strategy-denying having disease means not having to deal with it</p> <p>Possible Communication Message: Address misconception that a) diabetes is a death sentence b) that it automatically means insulin. Diabetes is a manageable disease</p>

## SUMMARY: DISCUSSION TOPIC TWO-NUTRITION

	Barriers to Healthy Eating	Benefits to Healthy Eating
<p>The Hui discussions made clear that in conceptualizing health campaigns and messages, we need to move beyond the simplistic notion that Māori don't know they are sometimes making poor food choices. They do. The challenge is <u>how</u> to make those changes.</p> <p><b>Times Have Changed: Past v Future</b></p> <p>Women lament how changes in lifestyle negatively impact diet- note a political/environmental perspective-e.g. pollution is a threat to traditional food gathering</p> <p>Possible POV that needs to be acknowledged in film</p> <p>Majority of women are still in charge of food shopping/meal providing for the family</p> <p>Hui participants discussed their struggles with diet/Kai, some reporting feeling bad about making poor choices sometimes. Possible Communication Message: It's okay to slip up now and then- everyone's human!</p> <p>KIs have discussed strategies they use to overcome barriers- it's about small incremental changes Possible Communication Message</p>	<ul style="list-style-type: none"> <li>• Upbringing: socio economic status = large family, poor diet and lack of access and information about/to healthy food</li> <li>• Takeaways-quick and convenient</li> </ul> <p><i>Potential message: It's all about moderation. Try and cut down the amount of take away meals per week.</i></p> <ul style="list-style-type: none"> <li>• Pollution/lack of clean coastline for fishing.</li> <li>• Cost. Healthy food is more expensive than unhealthy food</li> <li>• Cultural traditions: idea big is good or that you must eat everything on the plate</li> <li>• Convincing whanau to change habits. Particularly difficult to persuade main cook to change</li> <li>• Ignorance/ lack of information on healthy foods (particularly true of teenagers)</li> <li>• Social Marketing-TV advertising and flyers</li> </ul>	<ul style="list-style-type: none"> <li>• Feel better and healthier</li> <li>• Weight loss</li> <li>• Confidence</li> <li>• Ability to be there for mokopuna <b>KEY POINT</b></li> </ul>

## SUMMARY DISCUSSION TOPIC TWO-EXERCISE

	Barriers to exercise	Benefits of Exercise
<p><b>Definitions of Good Health</b>                      --staying healthy for the whanau (being there for mokopuna) <b>KEY POINT</b></p> <p>Possible Communication Message</p> <p><b>Definitions of Exercise</b>                      --range of views expressed. Encompassing the expected (gym, running etc.) to circulation exercises watching TV.</p> <p>Possible Communication Message--Need to acknowledge variety of activities that can constitute exercise-not just the gym. Also need to recognize people's physical limitations (realistic goals)</p> <p><b>Who is Exercising?</b>                      --MND all exercise. Only one MWD exercises                      --People with support-from partner/children/friend                      --Only one FWD exercises</p>	<ul style="list-style-type: none"> <li>Expense/Cost  <i>Potential Message-exercise can be free-e.g. walking</i></li> <li>Stress/family problems  <i>Potential Message-exercise can relieve stress</i></li> <li>Time  <i>Potential Message-can do a few minutes each day-every little helps</i></li> <li>Tiredness  <i>Potential Message-don't have to exercise every day or do too much</i></li> <li>Physical limitations e.g. operation on leg, physical pain etc.  <i>Potential Message-find an activity that suits you</i></li> <li>Shyness/lack of confidence  <i>Potential Message--Programmes out there for people who are just like you-He Waka Tapu, Whanau Tautoka etc.</i></li> <li>Laziness/lack of motivation</li> <li>Earthquake disruption</li> </ul> <p>Possible approach to video: Self efficacy/social modelling: Follow someone acknowledging these barriers and discussing their strategies for overcoming</p>	<ul style="list-style-type: none"> <li>Older Participants-want to be there for/physically capable of handling mokopuna</li> <li>Younger male participants-feels good/confidence/attract women</li> <li>Opportunity to be with friends</li> <li>Weight control</li> <li>Diabetes Management</li> </ul> <p><i>Potential messages: weight loss--increased energy, improved appearance, added years of life</i></p>

## Appendix I. Documentary script

### I Want to Walk with my Moko: Preventing Type 2 Diabetes

<p>Sir Mark Solomon, Chairman Te Runanga o Ngāi Tahu</p> <p><i>Translation</i></p>	<p><i>Remember the connection between the life essence and the depths of the human heart. My first greeting is to the God who made all things.</i></p> <p><i>And to our loved ones who have gone ahead and cleared the pathway. You will always be remembered. May you rest in peace.</i></p> <p><i>Now to us who are here today. Greetings and acknowledgement to you all.</i></p> <p><i>I am humbled to represent Ngāi Tahu in the discussions around this important issue which is about the health of Ngāi Tahu people, indeed the health and wellbeing of all</i></p>
<p>Pete Mason, Chairman, Te Rūnanga Ō Ngā Matawaka</p> <p><i>Translation</i></p>	<p><i>At the beginning of my mihi I used an old proverb that means let us unite with father sky above. Let us unite with mother earth below. Let us unite with all of the people of the world. The dawn awaits. The night awaits for the beginning of the universe as we know it will be the best of life.</i></p> <p><i>I then went on to identify my mountain, my waka, my river, my iwi and my hapu and my ancestor and I am their generation today. I acknowledged the creator for everything that he created. I went on to talk about diabetes and the motehuka- you know the sickness of sugar. I spoke about that it's a bad thing that happens to all of us and that my prayer is that if anyone in the family suffers from this sickness then they need to see their doctors or their nurses. I also said that there are a lot of Maori organisations that they can go to for support.</i></p>
Title screen	<b>I Want to Walk with my Moko: Preventing Type 2 Diabetes</b>
<p><b>Family scene</b> Leah Menage, Community Health worker</p> <p><b>KEY MESSAGE: Healthy change won't cost more money/take more time</b></p>	<p><b>Leah:</b> It's nice that you asked me to come to your house...and that you're getting involved with how to minimise Type 2 diabetes and you're going to be obviously a cool role model for our Maori community should you take some of these things on board.</p> <p>So what we're going to do is we're going to come up with a plan of the ideas that you guys <b>think that you could maybe change – some of the things that you do without costing you any</b></p>

	<p><b>money okay – and without changing your routine.</b> So ...think about ...some food ideas that you might want to look at changing in order to make some healthier choices and prevent diabetes. [10:39].</p>
<p><b><u>KNOWLEDGE MESSAGES:</u></b></p> <p><b>Diabetes is big problem for community but most don't know what it is</b> [Knowledge]</p> <p>Lee Tuki, Community and Public Health (CDHB)</p> <p>Wayne Smith, Maori Health Manager, Rural Canterbury PHO</p> <p><b>MESSAGE: Address misconception over cause</b> [Knowledge]</p> <p>Cut back to family scene</p> <p>Doctor Matea Gilles</p> <p><b>MESSAGE: It's lifestyle</b> [Knowledge]</p>	<p><b>Mark Solomon:</b> It's been called the silent killer. It's one of the biggest health issues facing Maori today:-</p> <p><b>Lee:</b> Type 2 diabetes right at this moment is prevalent for Maori because they're getting it younger....Maori are getting Type 2 diabetes and they're dying. And the sad thing is it's preventable – simple things can prevent it.</p> <p><b>Wayne:</b> There's a couple of reasons why Type 2 is a major issue for Maori . One is lack of awareness of what Type 2 diabetes is</p> <p><b>Leah:</b> Do you guys know what Type 2 Diabetes is?</p> <p><b>Trevor/Boys:</b> No.</p> <p><b>Leah:</b> Nothing at all? Because actually it's a big problem for our Maori community and there's lots of people who actually have it.</p> <p><b>Matea:</b> The most common misconception just because I eat a lot of sugar I'll end up getting diabetes... - I ...impress upon people that there's a whole range of other factors.</p> <p><b>Wayne:</b> Yes there is diabetes within families - you could be genetically predisposed to diabetes. However, It is definitely lifestyle... a lifestyle of eating more – not exercising enough.</p> <p><b>Mattea:</b> Diabetes is a condition that makes it hard for your body to turn the food you eat into energy.</p> <p>Diabetes can have a very serious effect on your body. The serious effects cause an increased risk of heart attacks, stroke, kidney failure, blindness and possible amputation of limbs.</p>



<p><b>Back to Family Scene Day 1</b></p> <p><i>Note reflects, women's hui comment.</i></p> <p><b>KNOWLEDGE/BELIEVE MESSAGE:</b> It's about moderation</p> <p><b>KEY MESSAGE:</b> Set up for behaviour change: Having a plan</p> <p><b>What they want to do. Setting of personal goals</b></p> <p>Family goal: Reduce fizzy drinks</p> <p>Family goal: Milk</p> <p><b>KEY MESSAGE:</b> Small changes</p> <p><b>Setting of personal goals</b></p>	<p><b>Jodi:</b> We do have takeaways quite a bit. Just 'cause we do have quite a busy life and with the new baby so sometimes it is hard to ah ....</p> <p><b>Trevor:</b> It's convenient.</p> <p><b>Jodi:</b> And when we get home and especially after a long day at work it's easy and quick to go down and get some takeaways so we wanted to change that.</p> <p><b>Jodi:</b> Yeah. The boys probably ...</p> <p><b>Trevor:</b> Don't want to change it.</p> <p><b>Jodi:</b> The boys enjoy the takeaways.</p> <p><b>Keane:</b> We normally have like Burger King and McDonalds and fish and chips.</p> <p><b>Leah:</b> It's okay to have fish and chips every now and then but not a regular thing...</p> <p><b>Jodi:</b> I suppose one of the reasons we do have takeaways is because we haven't done the grocery shopping so I think definitely having a plan to have groceries for the week.</p> <p><b>Jodi:</b> We have a lot of fizzy don't we?</p> <p><b>Keane:</b> I want to start drinking more water.</p> <p><b>Leah:</b> And in terms of milk too there's like – there's the blue milk and then there's the light blue and there's the green. So the further down you go in those colours...the less fat there is.</p> <p><b>Jodi:</b> And maybe we don't have to go so drastic as to go green [<b>Trevor</b> <i>no – no – no</i>] – we could go light blue.</p> <p><b>Leah:</b> We are just looking at small changes</p> <p><b>Trevor:</b> I can kick the fizzy but I'm not kicking the blue.</p> <p><b>Trevor:</b> (to baby) You can't change your milk eh?</p> <p><b>Leah:</b> What about brown bread instead of white bread?</p>

<p><b>KNOWLEDGE/BELIEVE MESSAGE:</b> Diabetes can be prevented [Persuatory Efficacy]</p> <p>[Persuatory Efficacy]</p>	<p><b>Trevor:</b> That would be pretty hard</p> <p><b>Leah:</b> But if you eat brown bread that actually keeps you fuller for longer and so you won't need to eat as much either-it's a lot more filling</p> <p><b>Trevor:</b> I might try it</p> <p><b>Leah:</b> And how about you know when trimming the fat off your meat when you're doing the boil up or chops?</p> <p><b>Trevor:</b> It's the best part. (pause) Yeah we can give it a go I suppose.</p> <p><b>Leah:</b> And together as a whanau you can do it together, support one another, [2:38] that would be awesome.</p> <p><b>Leah:</b> And prevention is always better than cure.</p> <p><b>Lee:</b> It's really easy whanau – how can you prevent Type 2 diabetes? Good kai and being active – small changes – simple as that</p> <p><b>Mark Solomon</b> Our tipuna did not have the fast foods, the saturated fats. We need to embrace the old ways ...of eating healthy foods and being a lot more active than we are today in our modern world. Undertaking these little steps – healthy foods – ...more physical activity – is a very easy path to preventing this disease – affecting the whole whanau.</p>
<p><b><u>PETE AND RA'S STORY</u></b></p> <p>Pete and Lynne interacting with grandkids Building lego</p>	<p><b>Pete:</b> Hey guys, you know Koru's got diabetes aye?</p> <p><b>C:</b> Mhm hmh.</p> <p><b>Pete:</b> Do you know what diabetes is?</p> <p><b>C:</b> No.</p> <p><b>Pete:</b> You know why your Mum and Dad don't give you too many lollies?</p> <p><b>C:</b> Mm.</p> <p><b>Pete:</b> Why?</p>



<p><b>KNOWLEDGE MESSAGE; Obesity/weight causes Diabetes</b></p> <p>Ra Dallas</p> <p><b>KNOWLEDGE/BELIVE MESSAGE</b> Misconception : Diabetes is NOT a death sentence</p> <p><b>KNOWLEDGE/BELIEVE MESSAGE: Life style changes can prevent. : Diabetes is NOT a</b></p>	<p>C: Might end up like you.</p> <p><b>Pete:</b> What - tall, dark and handsome? Yeah you're right Moko. You're right, you might end up like me. Because when Koro was young, Koro used to eat all the rubbish and now I've got this [matihuka]. Because I've been eating the wrong kai, ever since I was a young fella</p> <p><b>Pete</b> When I was first diagnosed with diabetes I was very overweight. I'd ballooned up to 120 kilograms. We'd go out for a walk with friends and about 5 minutes later I couldn't carry on... I was short-winded and it was quite an embarrassment. And it got worse. It got so bad that I couldn't breathe and I sort of became a hermit.</p> <p>I think I was heading for a short stay on this earth and I was ready to join Papatuanuku</p> <p><b>Wayne:</b> Weight gain in men causes Type 2 diabetes later in life. Traditionally men haven't been that concerned about health and as you age you become less concerned about it—you start to put on weight-you become less active</p> <p><b>Ra:</b> I never thought I had diabetes. I just thought I was a big boned brother</p> <p><b>Ra:</b> I think I was 34 years old...when I first found out I had diabetes. I was 142 kg ...I thought oh no here we go – I'm going to go blind..– you hear all the real tragic stories of some whanau members who have diabetes</p> <p>My doctor told me if it don't take medication things will change for the worst. I'm trying to stop that before it happens</p> <p><b>Pete:</b> like back home where I come from, people dying of diabetes seemed to be the norm</p> <p><b>Wayne:</b> We're looking at a disease that for generations has affected many families... you're seeing the deaths within your family or you've seen the amputation of limbs – it becomes normal. - and so it's considered as a death sentence. It certainly isn't a death sentence - it's simple life changes can change all of that.</p> <p><b>Pete:</b> My eating habits were atrocious. Everything fried. I learned to eat properly and I</p>
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<p>death sentence</p> <p>[Vicarious Efficacy] Skills building and performance mastery</p> <p>[Persuatory Efficacy]</p> <p>[Vicarious Efficacy] Skills building and performance mastery</p> <p><b>MESSAGE: Cut back on fat/takeaways—</b> <b>MESSAGE: It's about moderation</b></p>	<p>learned what was good for me. We tried to cut down on my calories and fat foods.</p> <p>I never thought I'd see the day when I'd prefer some health food over a steak or pork bones...But slowly, for me, it was my change in eating habits. [.54]</p> <p><b>Ra:</b> We buy all these mod cons and we buy all these cool things but really we don't invest in ourselves . We need to invest in ourselves. Why not invest in ourselves to live longer? ....That's been the biggest thing for me has been learning how to cook.</p> <p><b>Ra:</b> You just learn different things you can do with food. Instead of eating takeaways every day – every meal –...just cut back – ...– try and have a home cooked meal –...– even the smallest change can be huge</p> <p><b>Wayne:</b> It's all about moderation. When we're looking at achieving wellness it's very simple – it's calories in and calories out. If one exceeds the other – especially the calories in – you're going to be unwell.</p>
<p><b><u>Family Scene-THE PLAN</u></b></p> <p><b>Encouragement of performance mastery Skills Building</b></p> <p><i>Based on feedback from women's Hui</i></p> <p><b>MESSAGE: Small steps</b></p>	<p><b>Leah:</b> So when I was here last we had a chat and you wanted to change a few things and have a plan for when you do your shopping... So if we plan the whole week and when you do the shopping you can buy everything you need and then we can stick with the plan. How does that sound?</p> <p><b>Jodi:</b> Yeah I think that planning our dinner meal would stop us from having takeaways.</p>

<p>Swap takeaway for baked or home cooked food</p> <p>Reduce fat on boil ups</p> <p>Leah and Boys prepping Sushi-whanua based</p> <p><b>MESSAGE: A plan will save you time and money</b></p>	<p><b>Leah:</b> ...and one of the options that we talked about was maybe some frozen or baked fish with some wedges.</p> <p><b>Jodi:</b> Okay – sounds easy.</p> <p><b>Leah:</b> and bake them so they're not in oil or fat.</p> <p><b>Leah</b> Wednesday?</p> <p><b>Jodi:</b> We could have the boil up...and maybe trim some of the meat or buy meat that actually hasn't got a lot of fat on it.</p> <p><b>Jodi:</b> I don't really like the fat – my Trevor does like the fat.</p> <p><b>Leah:</b> He won't know if it's not there.</p> <p><b>Jodi:</b> He won't know if it's not there.</p> <p><b>Leah</b> Nice veges [yeah] – try and cover it up.</p> <p><b>Leah:</b> making the sushi is going to be lots of fun for you as a family and doing it together....And it's great to get them involved in healthy food.</p> <p><b>Jodi::</b> Because then they're more likely to eat it.</p> <p><b>Leah:</b> Yeah cause they know what's in it and they've helped prepare it.</p> <p><b>Jodi:</b> Friday we could try the homemade burgers</p> <p><b>Leah:</b> That's cutting the fat down and if you stick to this it's actually going to save you time...you won't have to go out and get it</p> <p><b>Jodi:</b> It will save us money as well</p> <p><b>Leah:</b> So what do you think guys?</p> <p><b>Quin:</b> Can I have some more?</p>
<p><b><u>EXERCISE</u></b></p> <p><b>[Vicarious Efficacy]</b></p>	<p><b>Dalice:</b> For many years I had been a little overweight and probably not as healthy as I could have been...so there was a choice offered to me ...a community organisation...offered gym training –...help with nutrition and how to live a healthy lifestyle and how to make some good</p>

**BENEFITS OF EXERCISE**  
**[Positive Outcome Expectancies]**

**MESSAGE: Chose something you like/Buddy up**

**[Persuatory Efficacy]**

choices And that's been quite awesome in helping me get healthy – and pass that onto my whanau as well – wider included.

I'm stronger – I'm a couple of dress sizes smaller. It is just a part of life – a part of busy life. And so like if I've been working all day and I can make it to the gym – I'll make it – you know – I'll just do it – no excuses.– it's just like having breakfast for me – and if I don't go I don't feel good.

**Ra:** I help Lincoln High School with their kapa haka. I love kapa haka ...it's been a constant for me...its in my blood now

It's all about the body ... back in the 1700s ...Maori people...we're not built the way they are now. They would have been – muscular – fast – agile –..we still try and be physical through Kapa haka... If you're wearing next to nothing – looking good's probably a good option!

Diabetes is a killer for our people. It really is. And we have got to make the changes now.

I've lost weight in my kapa haka – I can jump higher... breathe easier Since losing weight ...knowing how my body can move – what it can do – what it can't do – – it's done a lot for me – more than I can explain actually. ...I've put it down to the – the choices I've made living more healthier –

**Lee:** Some people like to play ball sports, some people like to dance, some people really don't like running, some people like walking – it's finding what you like to do. Because if it's something you like to do – you're going to do it....– so find what you love to do first. [1:03]

**Mark:** Quite a number of my whanau do have diabetes and ...there is a bit of fatalism that this is something that we are going to get because it's in the family. But I don't hold with that. ...

When you look at it it is up to us. Don't take the fatalistic approach...just do the work. We've got to make behaviour changes. I've got to watch what I eat. I've got to make sure that I'm getting exercise .By being vigilant I'm going to make sure that I'm here for the long term for my grandchildren

<p><b>[Positive Outcome Expectancies]</b></p>	
<p><b><u>SO WHAT'S YOUR EXCUSE? EXERCISE</u></b></p> <p><i>Addressing barriers identified in Hui</i></p>	<p><b>Ra</b> The excuses why you shouldn't? ...I don't know – there's so many and I've probably said them all – too busy – can't go for a run – oh no my shoes are in the other car – oh I can't go to the gym tonight because my gym buddy's not going and so I'm not going – can't go for a swim tonight – I've got no togs. Okay – there's so many excuses ...I don't know – how much time do we have? I know them all – I know them all.</p> <p><b>Ra</b> Top reasons given for not being active or exercising. It's too expensive to exercise</p> <p><b>Lee</b> How much does it cost to go for a walk? Nothing. How much does it cost to go out to your back steps and step up and down your steps? You don't need to go to a step class – you can do that at home. How much does it cost to go skipping with your children – throwing a ball – it doesn't cost anything!</p> <p><b>Ra:</b> I haven't got any time</p> <p><b>Wayne:</b> Look we're all busy. If you want to make an investment in your life – longer life – see your children – grandchildren – you have a responsibility to find time to keep well.</p> <p><b>Lee:</b> I think it's about realising the priority – you are a priority...If you don't look after yourself, how can you look after anybody else?</p> <p><b>Ra:</b> I don't know where to start</p> <p><b>Mark:</b> Everything's about moderation. When I first got into walking – hell – 2km and I was nearly dying. I can do a 10km walk as good as gold now. So it's just about take the first steps – get active – it's not pleasant at the start but it gets a lot better – and you do feel a lot better.</p> <p><b>Ra:</b> I don't like exercising on my own</p> <p><b>Mark:</b> I would say that you need to make it a family subject - it's not just about Poa and Toa or Mum and Dad – it's about the whole whanau.</p>
<p><b>[Outcome Expectancy]</b> It's about whanau</p>	
<p><b>[Persuasory Efficacy]</b></p>	
<p>It's about whanau</p>	
<p><b><u>Family Scene: EXERCISE</u></b></p>	
<p><b>Message: Try to get moving. Huff and puff</b> Small steps</p>	<p><b>Leah:</b> Do you think there's any ways that you could add some more movement into your day</p>

<p><i>Implementation of ideas discussed at women's Hui</i></p> <p><b>[Performance Mastery]</b> <b>[Vicarious Efficacy]</b></p> <p><b>[Persuatory Efficacy]</b></p>	<p>and just keep you a little bit more active and get your heart rate up a little bit? Cause we know that if you huff and puff that's actually really good for our body and gets our heart rate up.</p> <p><b>Leah:</b> I think you had an idea ...about maybe you doing a bit of dancing in between the ads on TV ...– with baby?</p> <p>Jodi agrees</p> <p><b>Jodi:</b> We can walk a bit further. We've got a vege shop that's close by.</p> <p><b>Jodi:</b> Just little things I think as well...we go to the mall and the supermarket parking as far away from the front door as we can...small changes</p> <p><b>Lee:</b> The really good thing about exercise – it doesn't have to be ...going to the gym or joining a team sport or thinking of all the traditional things to be active. There's really simple ways to be active. When you come to an escalator and the stairs' right beside it – take the stairs – great – you've built in some activity in your day.</p>
<p><b><u>Family Scene: HEALTHY BOIL UPS</u></b></p> <p><i>Implementation of ideas discussed at women's Hui</i></p> <p><b>[Performance Mastery]</b> <b>[Vicarious Efficacy]</b></p> <p><b>[Vicarious Efficacy]</b></p> <p><b>[Vicarious Efficacy]</b></p>	<p><b>Leah:</b> So tonight what are we going to be cooking?</p> <p><b>Jodi:</b> Tonight we're doing the boil up and we're going to do it...healthy style. So we're going to boil the bones and then tip off that ...fatty bone water – and then ...we're going to add fresh water to cook the vegetables in.</p> <p><b>Leah:</b> So when we were last here ...we talked about a plan...how that been going for you guys?</p> <p><b>Jodi:</b> Cool...we had the baked fish and wedges...they were really easy...just put it all in the oven</p> <p><b>Leah:</b> And that would have been a lot healthier as well... Cause you baked it and it wasn't fried – that's awesome. So how about the water</p> <p><b>Jodi:</b> It actually gave me a shock yesterday – I saw Quinn drinking water out of a cup...</p> <p>I think the thing that has surprised me is that...they're doing the changes without much of a fight. I thought that they would really struggle not having fizzy and ...even just trying the brown bread - but they're actually pretty good. It's</p>

<p><b>MESSAGE: Reinforce plan/time/money argument</b></p> <p><b>[Vicarious Efficacy]</b></p>	<p>probably me – it was all me – I thought they wouldn't have done it so I didn't try. But actually I'm really proud of the boys especially.</p> <p><b>Leah:</b> And so...you're not planning on takeaways obviously?</p> <p><b>Jodi</b> No – ...I think the planning has definitely helped because I know what we're having for dinner.</p> <p><b>Leah:</b> How's Trevor getting on?</p> <p><b>Jodi:</b> not too bad... I noticed this morning that he had used the brown bread to make his sandwiches.... so he saw the light blue milk and he was like oh you know – I don't know about using that – but now he is giving it a go.</p>
<p><b><u>WHAT'S YOUR EXCUSE? KAI</u></b></p> <p><i>Addressing barriers identified in Hui</i></p>	<p><b>Ra:</b> Top reasons given for not eating healthy kai. Our tradition is that big is good</p> <p><b>Wayne:</b> The display of food in any culture is the display of one's mana. However that food can be healthy. You can put on a [hakiri] or a feast and choose the right foods.</p> <p><b>Ra:</b> Healthy food is rabbit food</p> <p><b>Lee:</b> No way! It's what you do and what you prepare...</p> <p><b>Ra:</b> My family don't want to change</p> <p><b>Pete:</b> I would say to them if you want to go to an early grave carry on. That's the bottom line. If you want to play with your grandchildren you need to be fit.</p>
<p><b><u>Family Scene: WRAP UP</u></b></p> <p><b>[Performance Mastery]</b> <b>[Vicarious Efficacy]</b></p>	<p><b>Leah:</b> How was the boil up?</p> <p><b>Jodi:</b> It went really well– we didn't even taste the difference... Quinn was the first one to try it and he just sat there and – “it's the same, it's the same” – and went and got some more.</p> <p>I think we'll definitely keep on trying the light blue milk...and the brown bread... Definitely trying not to drink the fizzy – not buying the fizzy is definitely helping. Like I said if I don't buy it we can't have it</p> <p><b>Leah:</b> Have you done any extra movement in your day?</p>

<p><b>IMPT:</b> Showing two healthy tasks being performed at once</p>   <p><b>MESSAGE:</b> Home cooked food is more nutritious and cheaper than takeaways</p>   <p>[Vicarious Efficacy] Collective efficacy-have achieved as a whanau/family</p>          <p>[Persuasory Efficacy]</p>	<p><b>Jodi:</b> We did actually walk down to the veggie shop today and that didn't feel like exercise cause I needed to go there.</p> <p><b>Leah:</b> Were you huffing and puffing?</p> <p><b>Jodi:</b> Yeah</p> <p><b>Leah:</b> Well obviously you are saving</p> <p><b>Jodi:</b> Well usually when we would go to Burger King it would cost maybe \$40... and this would have only costed maybe \$20 – if that –</p> <p><b>Leah:</b> So how have you found this week with some of the changes?</p> <p><b>Quin:</b> the boil up was nice – better than the other one.</p> <p><b>Trevor:</b> It wasn't as greasy – I know that much.</p> <p><b>Leah:</b> Would you like this as opposed to takeaways? What would you prefer – making your own burger?</p> <p><b>Quin</b> Making our own burger.</p> <p><b>Leah:</b> And those chips have actually just been baked in the oven ...they're not deep fried like at the fish and chip shop so they're actually way healthier for you. You won't be getting Type 2 diabetes real soon will you?</p> <p><b>Quin:</b> Hopefully not!</p> <p><b>Leah:</b> So what advice would you give to other families who wanted to perhaps try some healthier changes in their lives –</p> <p><b>Jodi:</b> Probably to trust their family – that they will be willing to make the changes – cause that was one thing that really, really surprised me was that they actually tried.</p> <p><b>Trevor:</b> Give it a go...It's not that hard...the foods just a nice.</p> <p><b>Quinn:</b> Delicious</p>
<p><b>BENEFITS:</b> Outcome Expectancies</p> <p>Increased energy/less stress</p>	<p><b>Lee 9929:</b> [5:35] The funniest thing I heard was a friend of mine she wasn't very active and then she started walking and she was walking all the</p>



<p><b>Being an active part of the community</b></p> <p><b>Self confidence</b></p> <p><b>KEY OUTCOME EXPECTANCY: Being there for Mokopuna</b></p>	<p>time. And she said Leah I just feel like I've got so much energy – and I said yes that's one of the bonuses of being active – you get a lot more energy and you feel energised.</p> <p><b>Pete 9T01:</b> [2:25] One of the benefits is I can walk more than 100 yards, physically I', much better...[11:42] It's about being able to go out and enjoy yourself, not sticking at home and being moody</p> <p><b>Lee 9930</b> [3:45] : When you've been active through the day you sleep much better at night time. You live longer. Your body – what's that old saying if you don't move it you're going to lose it. You actually start feeling more confident about yourself...and you start meeting people</p> <p><b>Wayne:</b> I think the benefits of having a healthy lifestyle is having the ability to get up and do whatever you want in that day ...It's about continuing to...participate in things that you've done as a younger person ...- it's being still an active member in society.</p> <p><b>Dalice:</b> You're doing it to stay healthy, live longer.... You're just going to have way more energy, you're going to feel stronger, you're going to feel proud, you're going to really increase that sense of pride and dignity in yourself.</p> <p><b>Lee:</b> You're going to live longer. You're going to be around for your grandchildren – for your mokopuna – and we all want to see our mokopuna – and maybe them to have moks. How wonderful would that be?</p> <p><b>Dalice:</b> You're a role model as a parent o it's important to be a good one for your kids</p> <p><b>Wayne:</b> As role models we have a responsibility to look well – to be well – and to participate in those events in later life. We're talking about 21<sup>st</sup> birthdays, weddings, the birth of grandchildren and in fact great grandchildren.</p> <p><b>Mark:</b> I don't want to be in a position where I've worked all my life, get to the age of retirement, and then I'm going to drop dead. I have a responsibility for myself but also for my family. And if I want to enjoy my grandchildren then I have to get active</p>
<p><b>CALL TO ACTION</b></p>	

## Appendix J. Supporting Letters



To the members of the committee:

My name is Wayne Smith. I am the Maori and Pacific Island Health Manager for the Rural Canterbury Primary Health Organisation. I was fortunate to be part of a collaborative approach in producing the DVD

*"I want to walk with my moko."*

From its inception a working group was established, members represented a number of key Maori stakeholders and Health Services. Our role was to support Alison to gain local knowledge, provide recommendations and to assist her in forming relationships with local community and health services.

We met regularly to provide regular feedback, ensuring content was acceptable relevant and an appropriate process was being adhered to.

Addressing Type 2 diabetes by filming Whanau in their own home, unscripted, totally resonates with those that are affected by diabetes. The grassroots approach is often more accepted by Whanau the fact that these families and service providers are known in our community, really personalises the message.

It takes a raft of skills to encourage Whanau to participate and divulge their personal health concerns - nonetheless with sincerity and respect.

It must be acknowledged that Alison Farmer demonstrated these skills and more. We trusted her and are thrilled with the outcome it encapsulates those groups most at risk, it contains us; it is about us, to help us.

I would imagine taking a more conservative approach would have been easier for Alison, however in my opinion that would have been less effective.

On behalf of the Rural Canterbury Primary Health Organisation's Chief Executive Bill Eschenbach, staff and management, I would like to thank Alison for her leadership and outstanding skills in producing this invaluable resource.

Na Wayne Smith

3<sup>rd</sup> December

2013

## June Swindells

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To: alison.farmer@pg.canterbury.ac.nz  
Subject: Letter of Support

*Tena Koutou Rau Rangatira*

*For the last three years I have observed and participated in the research undertaken by Alison Farmer regarding diabetes, at first, like many Maori, I thought this would be another duplicate of negative comments and statistics, but she soon captured my interest and I knew she wanted more.*

*Alison actually consulted and listened to community at all stages and quickly gained the trust that many researchers do not achieve, she tirelessly engaged in active participation and asked community members to help define research questions and strategies – a first time for many of us to be asked to contribute to research in this way!*

*When one knows one is respected, then one gives that respect back, Alison valued cultural protocols and beliefs in a manner that is consistent with one who has worked with other nationalities and in particular, indigenous peoples, a skill that is born from genuine participation. Her sensitivity developed relationships of mutual respect with leaders of our community, she honoured promises and commitments made, even after the horrendous earthquake in Canterbury, she came back home with her young baby and husband and fulfilled her commitments to our people and community, such was her dedication to her research and her own mana.*

*As one of Alison's community advisors, to develop discussion guidelines, recruit and serve as hui moderators, participate in hui and help to analyse results, and make recommendations for the documentary, I must say it was the most enjoyable hard work I have done because the leader of the project (Alison) never faltered in her obligations, even though another child was on the way, I have so much aroha and respect for this beautiful lady and her family support, that words seem insignificant to describe her inner strengths. Another wonderful change for me personally, was the way Alison worked on community strengths rather than highlighting problems or negative stereotypes, she paid attention to the social, economic and cultural conditions that influence health.*

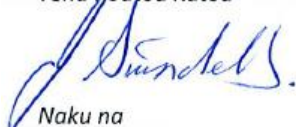
*I attended a launch of the completed documentary, "I Want to Walk With my Moko", at a Maori and Pacific Providers health hui at Rehua Marae in Christchurch, and I felt so proud of Alison because everybody at the hui could relate to the documentary, not just for the humour they understood, but for the serious message about lifestyle change and how as young people, adults and grandparents they influence the eating and health habits of mokopuna and future generations.*

*Thank you Alison for your determination and to you, Members of the Committee who made this documentary possible.*

*Ka nui te mihi, kia a koutou*

*Ka nui te aroha*

*Tena Koutou Katoa*



*Naku na*

*June Swindells*

18 December 2013

Dr Jeffrey Gage  
School of Health Sciences  
College of Education  
University of Canterbury  
Private Bag 4800  
Christchurch 8140

To Dr Gage

Reference Dissertation Research  
Alison Farmer

Alison Farmer came to me in 2010 in my previous role as CEO Partnership Health seeking support to undertake research and produce her DVD 'I want to walk with my MOKO'.

Despite the considerable disruption caused to us all in Canterbury in 2010 and 2011 Alison continued to work away consistently on her project. In particular she worked hard to engage the various players. She was clear about her requests for funding and other support and provided appropriate reporting on her activity related to funds given.

This was a community based research which aligned addressing aspects of priorities for the PHOs and Canterbury Health System. When the DVD has been viewed by a vast number of community people and health professionals it has stuck a cord for its engaging style and content. Her research on how Maori see diabetes has added to the debate here about how best to work with this community to improve health outcomes. For example, working directly with all members of a family on their eating and exercise habits has led to family members supporting each other to adopt healthier behaviours.

If you need any more details please feel free to contact me.

Thank you



Jane Cartwright  
Community Development Programme Director

Email: [Jane.Cartwright@pegasus.org.nz](mailto:Jane.Cartwright@pegasus.org.nz)